

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Still Sparkling After My AML Diagnosis: Casey's Story'

Description:

Listen in as Alicia and Lizette speak with Casey Biltz Marsh. Casey is a high school mathematics teacher and acute myeloid leukemia (AML) survivor. With Spring Break approaching, Casey noticed her extremely low energy however, attributed it to the demands of a high school teacher during that time. Soon after noticing this, having planned an amazing itinerary awaiting her parent's visit, Casey knew something was very wrong when they all attended a Garth Brooks concert and she found herself needing to pay the nearby shoe shining station multiple times just to be able to get off her feet. Join the conversation as Casey describes how her life changed after her fourth visit to Urgent Care. She shares how she was diagnosed, how she prepared for and recovered from her stem cell transplant, the importance of asking questions and maintaining a positive mindset even during the roughest times.

Transcript:

Alicia: Welcome to The Bloodline With LLS. I'm Alicia.

Lizette: And I'm Lizette. Thanks for joining us.

Alicia: Today we'll be speaking with Casey Biltz Marsh. Casey is a high school math teacher and acute myeloid leukemia, known as AML, survivor. Thank you so much for joining us today, Casey.

Casey Biltz Marsh: Y'all, thank you so much for *inviting* me on. I'm very excited to get to talk with everybody and I'm just thrilled to be given this opportunity. So, thank you so much for inviting me on.

Lizette: Well, thank you for sharing your story with us. It's not—

Casey: Absolutely.

Lizette: -not easy sometimes to relive your cancer journey, so thank you.

Alicia: Absolutely.

Alicia: In acute myeloid leukemia, known as AML, a series of mutations of the DNA of the myeloid stem cell result in the formation of leukemic blast cells that are stuck in the earliest stages of cell development. And these cells cannot mature into functioning adult blood cells, and then they then multiply uncontrollably. So, by the time that AML is actually diagnosed, the number of healthy blood cells is usually lower than normal. And at this point, that's when you have anemia, infection, or easy bleeding that may happen.

So, Casey, I understand that you were teaching when you were diagnosed. Can you tell us more about that time and what was going on?

Casey Biltz Marsh: Absolutely. So, even just your description does kind of remind me of all of, you know, the, the symptoms and kind of the signs that something was going on, but it was about this time last year. It was in the spring of 2018. And I teach Algebra 1 at the high school, and we were just coming up upon spring break. And I felt like every teacher feels right before spring break. I was just overwhelmed, I'm tired, I'm a little bit less motivated than normal, and I honestly just thought, okay, it's because spring break is coming up and I just need that mental week off, you know to get my act together. But as the days started, you know, progressing more and more, I was really getting tired, like, a lot. By the end of the day, I really just wanted to sit down. I could barely stand up anymore. I had a fever and this fever kept going on and off. I would take Tylenol; it would go down a little but would just come right back. It felt as almost I had a sore throat, earaches. And so, I went into an Urgent Care and, you know, they tested me for Strep that day and it, it came back negative. They said my ears were all good and that this is just going to be a virus, run it out.

So, I went on with my days. I finished school up, but I had some company coming in at the time. I had my parents coming to visit and normally, you know, I have a little to-do list, you know of attractions for them to go see, things to do. You know, I'll clean the house, get everything ready and I had zero energy to do that, which is weird because I'm very OCD, so I have, you know, everything that I like to do in my mind to get everything done and I physically could not do those things. I, I could go and do the dishes and in five minutes I had to sit back down. So I'm like, "This virus is literally kicking my butt." Like I don't, I don't understand. And I went back to Urgent Care and I said, "You know, maybe, maybe I need an antibiotic or something because maybe I just you know tested a false marker, you know, however they want to say that. And so I went back the second time and they said, "Well, okay, we'll try this antibiotic and, you know, you have to stay on it for this amount of days."

Lizette: Right, hmm.

Casey Biltz-Marsh: And I said, “Not a problem. Like, just anything to help me feel better.” And so, we tried that and I, and I really didn’t, you know, get any better from that. My parents did come into town. We did go around and do some things. I just had to sit down multiple times. And then we actually went to the rodeo – it’s a big thing down here in Houston – and we saw Garth Brooks. And I always bring this up because we only had standing-room-only tickets and I was not gonna miss this concert. Okay, I had to go. I mean, this is a big deal. And for him to come in right at rodeo, like, I had to show my parents. So, we went there, and I remember they have these boot cleaning stations, and I literally paid this guy just to sit up in one of those seats because I was so tired from standing. And I didn’t need my boots shined or cleaned ‘cause I had just had that done, and this guy was amazing. He just let me sit up there for a little while. But I managed to stand through that concert. And the next day, I ended up driving my parents back for their flight. And I went into Urgent Care again, this now being actually the fourth time, and that’s where they wouldn’t let me leave there without going to the ER. They said my heart rate had been up very high and my blood pressure was low and they said, “It’s a, kind of a critical condition so we’re not going allow you to drive yourself. We’ll either call an ambulance for you or you get someone to drive you to the ER.”

So, I called my neighbor that was home. She took me to the ER and after they did a round of bloodwork, they had found out that my hemoglobin level was at a 3.7. And it should naturally be up between 11 to 16 for a female my age. And, at that point, I just remember everything going downhill from there. Just sitting in the ER room, wondering, well, what does this mean? And at that time, I actually had one of the side effects, it hit my nerves, was Bell’s palsy showed up on the right side of my face. And so, as I was describing things to the doctor, my right side of my face kind of swooped down. And so that’s when they’re like—we’re going to transfer you to a hospital, nearby “-cause we’re kind of full at this point.” And so that became, my journey. And so, I went that night and I had a blood transfusion for the first time and the next day the doctors came in and they said, “Here’s the problem, we don’t know where your blood is. You don’t have any blood clots, we don’t have any internal bleeding, so we need to keep you here and investigate.” And that was on a Monday night that I had gone in and on Thursday morning, March 22nd of 2018, I was diagnosed with leukemia AML. So that’s how it all kind of, you know, hit. They were all pretty much just flu-like symptoms and, honestly, just questionable, but really that bloodwork is what told us something was going on in the body.

Alicia: Before this, had you heard of AML? Was this the first time you were even introduced to this term and this disease?

Casey Biltz Marsh: Absolutely. I am not one to be afraid to admit it, but I've heard of leukemia, but I really associated it with younger patients, you know, younger children and everything. And, I did know that it was a blood disease. I knew that type of cancer and everything, but, no, hearing, you know, even AML and breaking it down and just learning that process, that was all very new to me. I really did not know the basic, you know, knowledge of it. So, I had to learn a lot once the diagnosis came in. And not even just for myself but even to tell others, you know, when I'm, you know, trying to retell my story or—let somebody know, like, it was important that, that I relay that information correctly too, so.

Lizette: Sure. It's true. People hear of leukemia and not many people know that there's different types of leukemia. They call us all the time and, and we ask, "What type of—" you know, "What's your diagnosis?" And people say, "Leukemia." And then we'll ask, "So what type of leukemia do you have?" Because all the different types of leukemia have different treatments. They're different. You know, there's different prognosis. There's different ways to handle it. There's, acute leukemias like AML that you have that's more aggressive and typically needs to be treated right away. There's chronic forms of leukemia and, you know, really to educate people that if they are diagnosed with leukemia, just knowing that you have leukemia is not enough. You actually have to know what type of leukemia, so people could provide you with the accurate information that you need for your diagnosis.

So even, you know, you telling your story to people, you probably can't just say, you know, "I have AML" unless it's to somebody else that has leukemia that understands that there's different types of leukemia.

Casey Biltz Marsh: Absolutely. I had to practice saying the actual word out loud a lot so that I wouldn't mess it up. And, and I actually, I guess I threw all of the physicians for a loop at both of the hospitals I was at. The first one I originally went into you know, they, they were very certain it was leukemia, but there was a split between it being AML or ALL. I was actually showing some symptoms and signs of both. And so, they were taking a little bit longer to give me my diagnosis because they weren't positive on it. And when I went to my second hospital, which ends up being my treating, facility, they had the same issues. And so, they reran every test that they had already done, but they have to do it for themselves, and they ran into the same

issue but, eventually, it did come down to one cursor that that they found, and that's what made me have the diagnosis of AML.

Lizette: Wow!

Casey Biltz Marsh: Yeah. So, there was the time I was a little bit scared that I had both at the same time.

Alicia: Like Lizette mentioned, many will call us without knowing their exact subtype. I mean we know that it's important to receive up to date and relevant support or educational information for those to actually learn about their diagnosis, many people will go online and try to figure it out, but it's very, very important for people to know what exactly they are researching.

For those listening, we encourage you to visit www.LLS.org/booklets, or call one of our Information Specialists at 800-955-4572 Monday to Friday 9 AM to 9 PM Eastern Time to learn more about your leukemia subtype.

So, Casey, for you specifically, you went to the Urgent Care and then that's when they said, "We, we need you to actually go to the ER." Those listening and those that we speak to even on the podcast they say, "I wish I had known about this podcast when I was first diagnosed." So, for that person who might be listening who was recently diagnosed, what questions should they ask if they were in your shoes?

Casey Biltz Marsh: Ask every single question you could think of to be honest. I wouldn't even, you know, Google what question. I would just ask everything that was going on in your head. You know, "What's the next step? What do we need to ha-? What do I need to do? What, you know, what's the best thing that I could do to care for my body?" Because if we don't think about what the steps are ahead, then you think back to steps that you can't prevent, like what caused this.

We don't know what caused this. You can't think back in your head was, you know, was it something I drank? Was it something I ate? Have I been doing something wrong my entire life? You can't sit there and think about that, so you need to ask the questions that you can have to move forward. And so that's really what it was to me. Like I just thought in my head, like, if I had a question about, you know, what just that word acute meant, I asked it. And it might not necessarily have been, even been to my nurse or my doctor but I would find somebody that knew in that department and I would ask a question like that. And so, that's really what I can preach is just any question you have. And I know that I'm a teacher and so I will tell you that no

questions are stupid or dumb or anything, but, really, when it comes to that, like, sometimes we are living in a bubble when it comes to those diseases and we don't know. And so, we need people to help teach us and give us the knowledge of that. I don't know, any question that I had in my head, I would either write it down or I'd ask it right away. And so that was definitely, you know, the things that I had.

And another thing I always wanted to know is how long have they been doing a certain treatment or how long has something been going on. I want to know because they, they present you with so many trials and everything, and so you, you know, my curiosity is really what kind of provoked the questions. And then later on, you know, part of my treatment plan kind of go off on a little tangent here, but going through my first rounds of chemo, you know, they really helped. My body responded to that. But I also had a mutated chromosome, and so that was going to cause me to relapse later on, which brought a whole bunch of other questions, you know, that I needed to ask, and the doctors presented me with a stem cell transplant. And so that opened up a whole different, you know, Pandora's box compared to just leukemia. And so, that's when I really started looking into research and using the resources that, the hospital and even any like society like this presents you with. That's when I was really curious about, things and I started to ask more questions. Because that was a whole transplant was just way different than, to me than hearing chemo or something. Like I had no idea we could these types of things now.

Lizette: Right. That's a lot of questions. And I just want to tell you that I'm glad that you were persistent because we've talked to many people that kept going back to an Urgent Care facility and were, was given, you know, medication; told it was a virus; told, "Take this antibiotic." And, they said the exact same thing that you said, Casey, which was, you know, "I took the medication, it didn't work so then I went back to see if there was something else." And just to keep going back, just they're still ruling out what you have, and a lot of times they're not looking for leukemia. They're looking for the most prevalent thing that you can have, which is usually, you know, a cold or a virus. So just your persistence and everybody that we've talked to their persistence and keep going back to actually say, you know, "This didn't work for me. Let's see what else is happening." That's very important because we've had a lot of people that were diagnosed with an acute form of leukemia, that started out by going to these Urgent Care facilities. So, I'm glad that you kept going back.

Casey Biltz Marsh: Yeah, it's definitely about just understanding and knowing your body. And I was, you know, really optimistic about my health. Like I've, I've always been in good health. I've always felt pretty good. And when I was, you know, sick, it

was always allergies or some of that sort, so when I started having that fever on and off and, and I did have some night sweats, you know, very flu-like symptoms but testing negative for it eventually, you know, I had to tell myself, like, “Stop trying to be a hero and, and get through your day when something really isn’t right. Like I can’t make it through the day without laying down, that’s not me.”

And so, eventually, that’s what it took, you know, I had to break myself down a little bit and say, “Quit trying to be, this big person and, and go on when, when something is going on.” And, but to be honest, like that first night in the *ER* getting the blood transfusion, I really thought I would just get some blood and then move on—

Lizette: Hmm

Casey Biltz Marsh: -a week or two. I didn’t understand where my blood was going until the next day. They’re like, “That’s the problem. We don’t know where it’s going.” And so, when they said that to me, then it clicked in like, okay, so I’m here a while. This is, this is a big deal. So that’s really when it kind of sank in and everything.

But, you know, that’s, when it all just started going through my head like, “Okay, well, give me a fight and I’ll fight it.” Like I have no problem with that. Let me just put my blinders on and, you know, get through that. And I like how you said persistent because I’m big on words that start with P and they’re like, they’re power words to me. And with that power, like, a lot of what it’s gotten me through everything is, one, like the power of prayer. And whether that prayer is to anybody you could think of, even just talking to yourself, to me, is considered like a prayer.

Positivity; I’m all about being positive. You know, you just, you’ve got to roll with the punches and move forward. So, I think being positive is the best way to do that.

The power of persevering. Like you just, you go through it. So, every time I hear like a new P word, I get excited like to add to that *power* words to go through that because that’s important. I mean, I’m like a-anything that can kind of, you know, put a smile on your face or make you think of things and, and that’s exactly, like, as I go through the day, I’m big on looking at certain signs or seeing something and it, it’s funny but like even growing up, like my favorite color was orange. And then it’s like my sports team I’m from Cleveland, Ohio, originally and the Browns, their color is orange. I went to Bowling Green State University, their color is orange. And so, I know that I have leukemia, their color is orange. And so, you know, little things like that, but that’s how I make it into a positive thing for me is finding ways of not looking at it, you know, as a punishment or anything like that, but as a way, you know, to kind

of spread the positivity about it. And, you know, sometimes it, it's hard to accept that, and not just for the patient but, you know, for everybody that's involved with it. So, I just try to find those good optimistic things that will, lighten up the mood and spread the positive vibes instead of the stressing ones.

Alicia: Right, and I think it's so great that you, that you talk about the, the power or the importance of having that type of attitude. I mean we were speaking with, another survivor, and he was diagnosed with ALL and he, basically said the same thing in regards to how important it is to just have a, have your, even though this changes your life completely, to maintain that great attitude of, you know, if this is what I'm facing, then full steam ahead. Let's deal with it. Let's do what we can and let's remain positive while we do it because, that's what brings us through it. That's what, that's what encourages us and supports us and inspires not only us but our caregivers, those around us to kind of find that strength too.

So, I think it's so important for patients and for those listening and caregivers as well to hear someone like you say, you know, "This is what happened to me, but I'm not going to see it as punishment. I'm going to see this as a chance to just exercise this power that I either know that I have or don't know that I have, but now is the time to test it out?"

Casey Biltz Marsh: Exactly. It really, you know, I know it's so cliché to say, "Everything happens for a reason," but I know that I was chosen specifically for this task. And I say a task because, one, I'm a teacher and, you know, we have those to-do lists and everything. And to me, but it's I'm here for a reason. Not just, you know, being on this episode and getting to talk with everybody here, but I'm here for more important reasons and that's to make a huge, you know, picture of how people can beat this and how you can beat it optimistically and positively.

And, you know, I know not every treatment is the same and not everybody goes through that, but we have the choice to make it the best that we can. And that's what I feel like I'm here for is to encourage that. And even though we have, you know, downfalls that we hit, I mean there's definitely ways that you climb out of it. And that's what, like, I want everybody listening to hear is that even when you're there, you have somebody to help you through it. And it's not a battle that's by yourself. You don't have to be alone. And even if you don't have the closest support group, you have a million people worldwide just even thinking about you and praying and helping and, you know, just putting their, their stamp on something.

And, you know, this might be coming back to my competitive roots, I mean my, my support group was amazing and they came up with this quote on a T-shirt that said, "Whoever said winning isn't everything, obviously hasn't met me,". It was perfect, but it is. It's a task, it's a challenge, and it was one that I happily accepted. And I know that might sound funny to people because you don't want to have to be the one to battle it, but, honestly, I would, I would choose me over and over again because I'm ready to do it for everybody so that's just what- I think it's important for everybody to know that and just know how appreciative that, you know, just even a thought is helping somebody. And that's just what's important and close to my heart for that.

Lizette: Wow!

Alicia: That is so beautiful and moving. I've never heard someone verbalize it that way. You know, if it was me, I would choose me over and over and over again because I'm doing this for everyone. I think that's such a great testament to, your strength and to your impact and we pray and hope that you continue on the path that you're on because, I mean, we know that you're changing the lives of those that you come in contact with and, you know I mean patient or not, the lives are being changed by your experience, so thank you so much for that.

Casey Biltz Marsh: Of course! I mean I probably couldn't even repeat all of that again, but that's just how I truly feel and, you know, something.

Alicia: That's how you know it's real though.

Casey Biltz Marsh: If the roles were reversed and I was the caretaker or I was on the opposite end, I don't know that I would handle it so well to somebody so close. And so, being the patient and everything, that's where I, I really do try to be confident and, and positive and keep the strength and everything because if I was on the other end, I would need that from, the patient. I would need that to help me motivate them as well. And so, because sometimes, the caregivers go through things that are harder than us. And the way that I always explain it to, people from the outside is my goal as the patient was to fight the hardest I could. And so, my focus was making sure that I knew how my body felt and that I responded to things and that I asked questions and that I did my job as the patient.

But as the caregiver, you're having to take care of that patient, the household, the finances, if you have kids, pets, whatever. So, it's like- and they still have to run their lives. So, they're just juggling everything and, it just can't go unnoticed.

Alicia: Um-hmm.

Casey Biltz Marsh: It's fabulous what the caregivers and all the close people that are working with them do, because that really helps the patient because then we just have to focus on us.

And that's what's great about LLS, The Leukemia & Lymphoma Society is that those people are there to help families and people going through this at any second with whatever help we need. So, if you're not even sure who to talk to or what resources you have, you have the Society to help with that. And that's just what's important, like, to me now is working with the Society and making sure that all the patients that go through this know that they're not alone and it can help the caregiver, it can help the patient in more ways than one.

So that's really kind of, you know, how I got involved too. And I know I'm going off on tangent again. But that's honestly how I got involved with the Society was my nurse actually brought it up to me in the hospital and I actually got a call from somebody at the Society. And I can't even remember exactly what the whole conversation was because I think it was just one of those days that I was like, "Why is my hospital phone ringing?" This is weird. Everybody calls your cell phone, so when you get a call at the hospital, you're like, "Hello." I think I was a little like, you know, shaken up.

But when I got out, my best friend said, "They're having a Light the Night for The Leukemia Society on October 27th, you have to come." And I said, "Oh my gosh, we have to do that." She says, "it'll be perfect." Well, it's perfect because it's my husband and I's wedding anniversary, and the first time we walked in Light the Night was our first-year wedding anniversary. So, can you imagine, you get married in October and then, your spouse is diagnosed in March. So, we were so proud and so honored to walk at that night as a couple together because it just shows, you know, that there's love and everything. And so, Light the Night and being part of the Society now is, it's huge to me. And I reached back out to them and now I get to help out as a volunteer and call their patients like myself. I'm actually helping our chapter here in Houston go out and spread the word about the Society and Light the Night. And I honestly feel like some of those are the reasons why I was chosen to go through this and everything was to make this difference and to get back out there. And since I was taken, you know, such good care of, I feel like it's my time to give back. So, it's awesome. And I love everything about it.

Alicia: I think it's awesome that you guys celebrated your one year at Light the Night. I mean for us, I went to my first Light the Night when I first started working here at

LLS and I brought my family, I brought my friends. I was just blown away. I was blown away by those just serving as support to others and survivors. And it was the most incredible experience, so I can only imagine how it was, being a newlywed couple having gone through what you went through at that type of event.

Casey Biltz Marsh: It was, I can't- see, I get speechless about it because I can't describe it, but it was so much fun. It really was. And it was a little bit emotional, you know, being around there, but you get almost like tingly throughout your body, like, just looking around and, seeing all the different lanterns and just everybody there. And, you know, when, you know, people are out there walking and stuff, like, it just, it creates a different atmosphere.

And that's what I loved was, I guess, you know, being out from, I don't, I mean what was it, like, six, six-seven months or something after that and being able to walk in something so soon and be there—

Lizette: Um-hmm.

Casey Biltz Marsh: -like I felt, you know, you guys are going to laugh at me, but I'm going to say I'm just going to feel all of my sparkles because that's how I am. You can't dull my sparkle and I just feel brighter and brighter every time I'm in those situations. And so that's why I will tell you nobody can dull your sparkle. Everybody, you know, gives some sort of spark and it creates a sparkle. So that's what it was to me that night is I just felt extra bright. I felt like one of the lanterns personally.

Alicia: Aw, that's awesome! And you know what, that's exactly why it's lanterns. It's to light the night, and it's a celebration of light to drive out the darkness of cancer. And it's such a great event for people to attend or speak with someone who has attended to, to hear their experience. And you also meet a lot of great people there as well. I remember when I first went, I heard so many stories and connected with so many people who were diagnosed a year from, that date. So, it's such a great time. And for those who would like to register for the event or, learn more about it and read more about it, you can visit www.lightthenight.org. But, Casey, going back to treatment just for a moment, with AML, intensive chemotherapy might be all a patient needs or, there might be other treatment options. You received a stem cell transplant from your brother. How was that process? How was, you know, preparing for that, recovering from that?

Casey Biltz Marsh: So, hearing about the stem cell transplant was kind of, you know, a little shock to me, just because I didn't know what it was or what they were

going to do. So eventually once I started looking into it more, I was like, "Oh my gosh, like, this is, this is really kind of awesome that, that we can do these types of things." And I was never hesitant or scared. I was ready. I'm like, "Okay, well, what's the next step?" Like, let's go. I don't want to wait half a year to do this. Like, when can we go?" So, they said, "Well, there's a process that you have to go through. We have to find you a match, and we have to, you know, you have to stay in remission, and we have to do all these different tests on you and everything." So immediately we started the process.

Well, it's lucky I come from a big family. I have three brothers and two sisters.

Lizette: Wow!

Casey Biltz Marsh: And three of them were perfect matches.

Lizette: Wow!

Casey Biltz Marsh: Yes.

Alicia: That is a blessing. Oh my gosh.

Lizette: That is a blessing.

Casey Biltz Marsh: I know. And sometimes I feel so guilty because I want to share 'em all with, you know, people that have trouble finding the donor, so I want to be like, "Oh, I have so many here."

And it did, you know, and a lot of my family is competitive like me, so they were all naturally like, "Well, I'm gonna be it. I'm gonna be the donor. I'm gonna" you know, "it's gotta be me. It's gotta be me." And so, what they did was they actually preferred to have a male. They, they told me that it was basically based off of your hormones and everything. Guys have a little bit less, you know, hormones to deal with than females.

Lizette: Yep.

Casey Biltz Marsh: And so, they chose my brother that's closest in age and closest in weight. And, again, as a sign, we would always call each other our twins growing up. We were pretty much the same height and the same weight for a long time. We told my younger sister that we were twins and we just had different birthdays because we didn't want to share it.

Alicia: That's funny.

Lizette: Oh.

Casey Biltz Marsh: She's pretty gullible, but so now coming back, it was kind of ironic that we really were going to kind of be twins now, you know, with the same blood. And he was great, and his work was great. They let him go and fly over from Florida over here and they did the process kind of like a dialysis where they took out his blood, you know, ran it through, filtered, took out the stem cells and then kind of flushed it back into his body, which was really great to kind of witness and see something so crazy like that happen. And they needed about, I think, 4 million stem cells from him and they actually collected 11 million stem cells.

Lizette: Wow!

Alicia: Wow!

Casey Biltz Marsh: It was, it was great. And so, once that process, you know, was there, it took about three days for him to do all that stuff. Then it was my turn. I did a few more tests and, and everything and got cleared. I was still in remission from my two rounds of chemo that I had. And when it came time to do my stem cells, it's fun 'cause, they give them through you just through an IV and you can hold up your cell phone to the little cords coming down from the IV and you can see the stem cells float down.

Lizette: Wow!

Alicia: Oh wow!

Casey Biltz Marsh: It was really hard to kind of, you know, capture in a picture on a phone, but I'll never forget what that looked like and, and everything.

And so, I had one big round of chemo right before that, and so a lot of my side effects or symptoms did come from the chemo and not necessarily that transplant right away.

And so then after that, my total stay there for that whole process was about 34 days in the hospital. And there was about, you know, two weeks I would say that was kind of like the low end of it just kind of feeling a little bit rough and dealing with some throat pain. But after that, they encourage you to walk every single day to get out there and get your strength and what not. And they have an exercise group, and I just

remember loved going to exercise group because it's like a social event for me. So, you got to see everybody.

And everyone shares what day they're on of their stem cell transplant. So, your first day that you get it, it's day 0. So, when you get to watch all those other people in the exercise group tell that they're on day 21 or, you know, day, 2 or something, you get to look forward to hearing their stories to see how you're going to kind of, go through it.

Lizette: Um-hmm.

Casey Biltz Marsh: Or vice versa, you get to share with those people that are just now going through it. So, it really helped having those types of things, you know, going through that transplant.

And once I was released from the hospital, I did have to go back every day for about two weeks just to watch your numbers and your counts and everything. But then after that, the doctors kind of start doing some treatments from home, you know, that you can do, just natural infusions and things like that. And now we're at the point that I'm almost one year out from my stem cell transplant.

Alicia: Yay!

Lizette: Congratulations!

Casey Biltz Marsh: Thank you. And I'm down to just small very minor, like, symptoms every once in a while, of something called graft-versus-host disease. And a lot of times, like, the easiest way to explain that to people is when I received my brother's stem cells, they try to take over your whole body. And so, when your body starts producing its own stem cells, my brother's just wants to take over. And so sometimes that causes them flare up symptoms which, you know, can be very mild or they can you know, be very offensive and stuff. But, luckily, mine has been a good recovery and, you know, I'm, I'm thankful and very blessed to how my recovery is going, but it's beyond me, how this research is done; it's crazy. And I love—

Lizette: Um-hmm.

Casey Biltz Marsh: -that we have people that are persistent and, curious and find ways to help us, get through this stuff. And, and that's just my view on that, the stem cells and how crazy it was to see something like that happen. But it's awesome and I'm like walking proof that, you know, it can go well.

Alicia: Absolutely.

Lizette: There's a lot of research now for AML and there hasn't been a lot of advances for AML treatment in the last 40 years. And LLS is leading the Beat AML Master Trial, which really is a groundbreaking collaborative clinical trial that's really testing novel targeted therapies for patients with AML. Patients go through genomic screening process that takes up to seven days, which in itself is something new 'cause usually patients with AML, start treatment right away, but we need to know their genetic profile because once we know a patient's genetic profile, the patient is then assigned to therapy based on their genetics. So, this is totally individualized to their genetic marker and we're working with a lot of different medications and treatments so we're really looking to give you the best medication and treatment that serves your AML, that serves your markers.

So, that's really something that's innovative as well as years ago, stem cell transplant was definitely innovative, something that was new and something that now throughout the years, the process has been getting better and better. And we're now talking about CAR T-cell, which really reengineering your, your own T cells, your body's own cells and reprogramming them so they can know what a cancer cell looks like and then they can go and kill the cancer cell. And that's your own body doing it.

Alicia: To add onto that, to think that there have been few advances in treatment for AML in 40 years is so crazy. Having LLS or LLS' aim to change that through this type of precision medicine approach is something that is exciting and hopefully, something that allows for there to be a change; that there will be a major, advance in this field and patients will be getting better news and, you know, the best news when it comes to, that day of being diagnosed because so many things run through your mind.

Casey, going back to the day that you were diagnosed and, you know, the weeks after that, where did you go for support, when you were looking to find out more about what the doctors had just told you? You know, how important was the support system at this time?

Casey Biltz Marsh: You know, I have a very, very close and personal support system and also a very large one. And when people heard my story, I had a lot of people just reach out to me, with similar stories or somebody else they knew that was going through AML. I mean I was, honestly, kind of flooded with resources and everything. But to be honest, my one go-to person was my aunt. And she's up in the Cleveland area and she has been an oncologist nurse, I don't even know how many years. She might be mad at me for saying that, but she's also in like the teaching field

now where she is, you know, learning all this education and going back and, and teaching others. And anytime I needed, you know, a vocabulary quiz or just anything like that, I went to her. She was kind of my, my home base of any question I had, or if she wasn't there, you know, she would be on speaker phone with the doctors and just be kind of able to relate, you know, that way.

And, you know, I'll never forget after I was diagnosed, one of the first questions; she was on the phone with the doctors and stuff and I just, I asked her, I said, "When can you fly down?" And she was here the next day to see me get off the ambulance and into the ER and, and what not. She was very much a solid stone for me to go to on all of that. But I also made really good connections with all of my nurses. And I love all of them dearly and, honestly, I would build those relationship and I got a lot of good follow-up from them. They would give me different resources. That's how I heard about The Leukemia & Lymphoma Society was from them. You know, they were the ones that would contact my social workers or counselors, anything like that and that's whether I was inpatient or outpatient. It didn't matter. You know, any of those nurses, anyone that I could talk to it was very beneficial from them. So, where I got my treatment, they provided a lot of different resources for me to use. But I did use very personal and close relationships that I had with people already. Those were my main support, you know, systems and everyone was just amazing on that.

And I mean the high school that I worked for they just, it was an outpour of help, whether it was from meals being delivered or blood drives in my name or even people donating days to me from work. Like everyone just truly stepped up and it was just overwhelming and crazy to think back to all of that and that's what just gives me that inspiration to, to keep going and giving back and giving more to everybody because time is just essential and it's precious to everybody. And so, they have stepped forward and helped me and that's what I feel like I need to do myself is to keep stepping forward and now helping others and everything.

So that's where my resources came from and now that's what I'm really trying to do is to help cry out all the different resources for people to use.

Alicia: The importance of community and support is just a point that we want to get across because I mean no one can do it alone and especially during such a challenging time like a, blood cancer diagnosis or any diagnosis for that matter, no one can do that alone. And so, I mean for those listening who would like to learn more about the support resources that LLS offers, whether it be our LLS patient community, whether it be an online chat that takes place weekly, there's so many different things that we

offer. So, we encourage you to visit www.LLS.org/support to see the listing of all those resources.

To your point, Casey, I mean, again, it's so important for people to hear someone who is in the same position say, this is who was rallying around me. This is what I needed. This was holding me up during this time. Because, again, you need that type of circle around you and that type of support. You're blessed to have it but sometimes people don't have that support.

And so that's why online support resources are important and are beneficial because it allows people to connect with others in the comfort of their homes in their pjs and, really ask the questions that maybe they thought that they couldn't, they didn't have anybody to ask at that time. So, thank you for sharing that.

Lizette: Hmm.

Casey Biltz Marsh: Absolutely. I mean the more people that know, more prayers go up, more miracles come down, so.

Alicia: Absolutely.

Alicia: So, on our Home Page, we have a line that says, "After diagnosis comes hope." And so, if you were to finish that sentence, what would you say? After diagnosis comes, fill in the blank.

Casey Biltz Marsh: Oh man. You all should've prompted me for this. I have no—

Alicia: We did it on purpose.

Casey Biltz Marsh: -place else I can go.

Lizette: You know what it is, she's looking for a P word that's why.

Casey Biltz Marsh: It's not even the P. You know what it is that I will go to is after diagnosis comes your biggest sparkle ever.

Alicia: There you go!

Lizette: Sparkle.

Alicia: And that's why I didn't prompt you because we want it to be a gut reaction, gut response what are you feeling at the moment. So that works 100%.

Casey Biltz Marsh: Right, yeah. Don't mind me with all the sparkleness. I've decided that at school I need to wear some sort of sparkle every Wednesday. I don't know why I chose that day. Maybe it's just 'cause it's the middle of the week, but I will have some sort of glitter or sparkle on every Wednesday.

Alicia: That is awesome! You sound like such a great person to just, to, one, to just know because you—

Lizette: Um-hmm.

Alicia: -have such a great personality, you have such a great kind of mindset towards things. So, I could only imagine how happy the students are having you as their teacher, especially in math because I mean, come on!

Lizette: Yeah, especially math.

Casey Biltz Marsh: Oh yeah. You wouldn't believe the looks I get for math.

Alicia: Listeners, unless you love math, then, hey, we're all about it.

Lizette: Yeah.

Casey Biltz Marsh: That's all right. Everyone needs a nerd, a math nerd like us to fill in those spots.

Alicia: Exactly. Exactly. We're all pieces of the puzzle somewhere somehow.

Casey Biltz Marsh: Right.

Lizette: Pieces of the pie. The only thing I like about math is National Pie Day. We actually get to eat pie, although it means the math Pi, but it doesn't matter.

Casey Biltz Marsh: It doesn't matter, a desert pie, it could be a pizza pie, we don't mind. We like to celebrate anyway.

Alicia: So, Casey, is there anything that you think that we did not mention on this episode that you think would be beneficial for our listeners?

Casey Biltz Marsh: The most thing I can really just try to assure people is to ask questions. You know, keep trying to find resources or answers that you're not getting. Don't just stop with one person. Just really keep going because somebody out there is listening. Somebody out there does want to help. They do want to know, but we

can't exactly do that without recognizing it. So, I just, I encourage people to be vocal about that.

And, you know, I told you guys before when I, we had talked on the, the phone I do something at the end of all of my, you know, talks and everything. And I definitely want to include a little bit of that on here. And it goes back to, you know, my sparkle. I didn't want anybody to ever, you know, look at it as a bad thing or, you know, that it dulls something. I want everyone to think of that sparkle. And, you know, when I was in treatment and everything, I never got to ring this bell that everyone talks about ending your chemo. And maybe it's because we didn't know if that was going to be the end of chemo or it's right into stem cell, but I was just never given that opportunity. And it made me think about all of the other people that haven't been given that opportunity either or just all the people that don't have someone to be their advocate or to vouch for them.

And so, when I go out in, in front of all these people, I bring these little jingle bells, and I pass these glitter jingle bells out. I do spray paint them with some glitter on there to sparkle. And I just give the jingle bell to each person that wants one. And all they have to do is think about someone that they can hold this bell for. And if they don't have anybody that they know personally, then I want them to think about all the people that might not have somebody.

And when they're doing that, what they're doing is creating that spark inside that jingle bell. And then as soon as we ring that bell, it's creating all those different sparks. And sparks turn into sparkle. And so that's just one thing I want everybody out there to know is even if you don't have that very close, you know, supporting system, you have all of us sitting over here ringing the bell for you.

So that's my, funny, little ending to everything, but I really truly feel like the bells make a difference to, to me because I haven't been, you know, one to ring it, so that's my little bell. Don't know if anyone can really hear that, but it means a lot to me and, you know, to be here today to get to do the bell and think about all those that might need us to ring the bell for them as well.

Alicia: That is so awesome. And I, honestly, do we even need an ending with that type of ending? That was perfect.

Casey Biltz Marsh: Right, it's like mic drop.



Alicia: Right, mic drop. Casey, thank you so much for chatting with us and sharing your story. You shared such great takeaways in today's—

Lizette: Yes.

Alicia: -episode that I think, I mean I know that Lizette and I learned from, from you today and I know that listeners will as well. And for those listening, we'd love to hear more about how you liked this episode, what you learned from this episode, so please comment below.

Casey Biltz Marsh: Awesome. Well, thank you both so much for having me on today. I honestly had so much fun, and I'm glad that we got to do this and, you know, I look forward to future podcasts and getting to let people know what we're doing here and how The Leukemia & Lymphoma Society can help us. So, thank you so much.