

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

Iva Ballou: Hey, everyone. Welcome back to the Love Meets Joy podcast on the Smile Train podcast network. I'm Iva Ballou CEO, and founder of RealSophisticatedJoy. And I am a cleft confidence coach who was also born with a bilateral cleft lip and palate.

Ashley Barbour: Hey everyone, I'm Ashley Barbour. And I was born with a bilateral cleft lip and palate as well. And I'm the creator of ClefttLove. By day I work as a teacher consultant with kids with hearing loss. And today I'm really excited because we're going to be talking about the specifics of our cleft journeys. We're going to talk about the types of cleft that we had, our surgeries, and we're going to get into some of the more emotional parts of this journey as well.

Iva: Oh, I don't know if we're ready, Ashley.

Ashley: We're always ready. But before we jump in Iva, did you have anything exciting happen this week? I feel like I'm so glad it's Friday,

Iva: That part majorly that part, but so something that interesting that happened to me this week, I think is a good tie-in to what we're going to talk about today is last night I had the opportunity to walk in a fashion show my first time ever doing so. And I can remember while walking, just being like, is this really my life now? Because younger Iva would've never, you know, were going to talk about how that sense of not feeling pretty was always a thing that I had growing up. So to be in a fashion show and have people come up to me afterwards saying that I was like, one of their favorite models was just surreal. So that's what's going on in my world.

Ashley: <laugh> we need that sort of representation in fashion. Absolutely. In movies on TV. And so I think that's really powerful, not only as a woman with a facial difference, but also an African American woman with a facial difference, I think is probably very powerful for, yes, not only people who have a facial difference or other African American women but just people in general to see someone with a difference and how beautiful you are.

Iva: Well, thank you. But yeah, that's exactly how it felt. It was like, oh, I'm actually showing up and it's not just for me, but other people. And it was just a really special moment. So that was just a little nice little way to end the week off.

Ashley: So exciting. That's definitely amazing. I know that we mentioned in the beginning, usually when we start off the podcast, we kind of talk about the type of clefts that we were born with. Yes. So we actually both were born with a bilateral cleft lip mm-hmm <affirmative>, but I know that yours was a little bit different than mine. Can you explain

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

Iva: How yes. So I had a complete bilateral cleft lip and palate. So what that means everyone is that it was on both sides of my upper lip. So the outer lip that you can see, and it went all the way into my nose. And then on the inside, the cleft was affecting the hard and soft parts of my palate. Ashley does an amazing job of explaining what that is. I promise everyone the first time I heard her tell it, I was like, oh my gosh, that's exactly what it is. And so the way to figure out what your palate is, is think about when you eat peanut butter, your tongue gets stuck at the roof of your mouth, and that is your palate. And I promise you when Ashley, like again, Ashley said it at one time and I was just like, these I've been searching how to describe it for 30 years and Ashley in one moment figured it out. So, but so that's what I have. <laugh> and Ashley, what about you?

Ashley: Yeah, so I actually had the complete bilateral cleft lip and palate as well, um, open on both sides, hard and soft palate. Basically when I was born, I didn't have much of a palate at all, which mm-hmm, <affirmative> made feeding really difficult. So at first they weren't sure how I was going to be able to be fed because there's no palate there. I wasn't able to establish suction at all in any

Iva: Way. Neither was I, neither was I at all.

Ashley: Yeah. It's actually kind of a, an interesting story. When my parents were in the hospital, a nurse, I think found think it was a four ounce glass bottle. My mom says, and then at the bottom of a drawer in the back somewhere, someone was able to find a lamb nipple, which is what you used to feed lambs on farm. Right. And it was really long and it was soft, like the consistency of a rubber glove. Okay. So, because it was so soft, I was able to just have it in my mouth and sort of bite down on it and express

Iva: It's kind of gum it.

Ashley: Yeah. Well, yeah. And just express milk. And it was so far back, it just went yeah. Into my throat without it coming out my nose. Right. And I know a lot of people, uh, born with, especially cleft have a difficult time nursing. Did you also have a hard time nursing? Were you able to be breastfed at all?

Iva: Not at all. Not at all. My mother said that I had a special bottle that she had to feed me with. I'll have to ask her what was up with the, the nipple part, but it definitely was the same situation, never breastfed. And just all of the time growing up, it was difficult with eating until it was finally repaired, which is something that we're going to get into the lovely things that come along with having a missing palate.

Ashley: <laugh> yeah. And I think something that is going to be really exciting for us to talk about in a future episode is we're going to actually have our moms on.

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

Iva: I know, I know.

Ashley: That's great. I totally can't wait for that to, to sort of hear what their experience was like. Mm-hmm <affirmative> and we'll be able to ask them more about what their experience was like, trying to feed us and what that felt like. Because I think there's a lot of stress on moms, especially to breastfeed and provide breast milk for your babies. And when you can't, I'm interested to talk to our moms about what that was like,

Iva: Right. Cause it's like, yes, there is stress about the breastfeeding, but it's also the main point is taking care of your child. And so I love the fact of our mom for like, by any means we're going to get it done.

Ashley: Yes. So for people who don't know a whole lot about cleft, I think it's important to note that a lot of times a feeding specialist is needed in the beginning soon after the baby's born. And a lot of times people think, oh, it's just a surgeon, but actually there's a whole bunch of people,

Iva: Whole team. And for the audience, for those who aren't cleft affected, like I think when my friends finally realized like, oh, every year you go and see multiple doctors. Yes. Like it's with birth, you are given at least a minimum of what maybe like six different doctors of different specialties.

Ashley: Yeah. There's a dentist and an orthodontist and a plastic surgeon and an

Iva: Oral surgeon, speech therapist as well,

Ashley: Speech therapist sometimes, uh, ENT, ear, nose and throat doctor mm-hmm <affirmative> uh, so there's just this whole wraparound team.

Iva: You also might have like a social worker, just, you know, just to make sure that you have other resources, it's a full village.

Ashley: People who don't understand or aren't familiar with cleft often think, oh, it's just a surgery and then you're done. But it's so multifaceted that it requires this whole team approach.

Iva: It really is a journey. We keep saying that, but it is a lifetime journey that it's never, even if that, that cleft affected person has one surgery, they still have other things that may go along with that into adulthood. So it's never just one surgery and it's fixed.

Ashley: Yeah. And something that I think many people have a memory of is the first time that they realize that they were different mm-hmm <affirmative> or maybe people

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

don't necessarily remember it, but maybe their parents remember a story of it. So do you, are you able to pinpoint a specific time?

Iva: So I have, I'm going to let my mother tell her story. I love when hearing her story for that. I mean, obviously, she always was aware of it, but she has one particular story. Um, she handled her far better than I did, but mine, I was about five and it was in daycare. Cause I went to like a really small family-oriented daycare. Everybody knew me, a lot of the kids I had grown up with, but then there was a new girl and I mean, granted, she was a kid, kids are inquisitive, especially for things that they don't know. Yeah. And just her response and reaction, it was, it was not bad. I do want to say that it was not bad, but it just made me feel othered and different.

Ashley: Yeah.

Iva: And in that moment it was like, okay, I am different. Because like I said, prior to that, we've grown up together. So it was just, oh, that's Iva. Um, but at that moment I became very aware that I was different and it seemed like from then on.

Ashley: Yeah. And then you just had that awareness in your head.

Iva: Yeah. It was almost like it was awakened. Like I became more, probably more conscious of it. It was probably always there, but I had never really paid attention because you're five, you're a kid you're, you know, living your best life. <laugh>

Ashley: Yeah. That's so true.

Iva: She made it aware to me that I was different.

Ashley: I feel like when I was growing up, something else that made me feel other or different was having to miss school for so many surgeries. How many surgeries have you had? Because that's something that's different for a lot of people in the cleft community. Sometimes there are common surgeries that we have, but the number of surgeries can range from one, for some people who have a very mild cleft all the way to, you know, 30, 40 everybody's number is kind of different. So how many of you had

Iva: It's 20,30? It, it, it was high.

Ashley: Really?

Iva: Yeah. It was high. Wow. But, uh, it was, some of them were like small little minor surgeries. Yeah. Like just trying to correct. And again, I also state that a lot. I would say like the last four to five of my surgeries were self-imposed because I

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

was searching for this sense of perfection that was never going to happen. So I will reference that like, yeah, maybe the last couple of them were because of me.

Ashley: Were those in adulthood?

Iva: Yes, they were, um, I had my last one, uh, 2010. So

Ashley: I'm like, oh, okay.

Iva: No, no, no, no. I think, yeah, no. Yeah. 2010 I believe. Mm. Um, like 21, 22 years old.

Ashley: Yeah. Yeah.

Iva: That was my last one. So how about you?

Ashley: I had six surgeries. Uh, so I had lip repair. Mm-hmm <affirmative> palate repair. Yep. When I was four, I had a lip revision mm-hmm <affirmative> and rhinoplasty. Same. And then I had a bone graft. Yes. And then I had jaw surgery and then I had my rhinoplasty. I feel like I'm missing one. I don't know what it was. But did you, when you had lip repair, did they repair each side separately?

Iva: No, they did them together.

Ashley: Yeah. They did both mine together as well. Yeah. But I just wondered if that was like one of your additional surgeries. No, because I know that they talked about potentially doing mine separately,

Iva: So there it did my lips, they then pulled it down because, so that way there was more spacing. Um, I think, I want to say like maybe three different rhinoplasties obviously had to fix the palate. I think they did two surgeries on that. I had the jaw reconstruction. That was fun. Mm-hmm <affirmative> mm-hmm <affirmative> and then of course my lovely, um,

Ashley: Bone graft,

Iva: Bone graft surgery. Mm-hmm <affirmative> um, and then I know I did have maybe one or two other surgeries. They weren't left directly related <laugh> yeah. Yeah. And so I, I was like six months old when I had my first one.

Ashley: Oh, okay.

Iva: Because they typically want you to have it your first one, between three months to a year. And so I had mine.

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

Ashley: Yes. Mine was three months.

Iva: Yeah. Yeah. I had mine at six months, so, and then another one I think at like nine months.

Ashley: So another question I have for you is like, what kind of patient were you? Because I think you and I have had conversations about this before <laugh> and I think we were very different patients.

Iva: So audience, you can't see it, but I am laughing hysterically right now because yes, Ashley and I are very different. So

Ashley: As patients yeah.

Iva: As patients. So first off because I was in the hospital so often I became like the welcome girl, like if there was new kids that were coming in for whatever surgery. Yeah. I was like, oh, it's going to be okay. I would say that I was a great patient.

Ashley: Um, like you were always happy like at the doctor and

Iva: I was happy, but I also, I needed to know everything that was going on. I was very much so wanting to know what is going on. What is the plan? Yeah, because again, I was, as, even as a young age was really searching, because I truly believe we've talked about this before Ashley. Like I truly believe that I could surgery my way out of having a cleft. Yeah. With my cleft, it went all the way up to my eye for a condition called Peters Anomaly. And even with that, it causes my left eye to tear up. I even looked into having a surgery to widen my tear ducts and they were like, well, we could do it, but it would always, basically I would look like I was always crying, which had already does that. So I was like, well, I can't do that. But that is how far I was willing to go to get rid of the cleft. I just really thought that I could become perfect.

Ashley: So were some of your surgeries included in that 20 number? Were some of those on your eye or your like eyelid?

Iva: I never had surgery on my eye or eyelid because I couldn't find anyone to do it, but if I could have, I would have, um gotcha. But a lot of it was, most of them came from my nose, um, because trying to get that

Ashley: As symmetrical

Iva: As possible. Yeah. Um, so how many, how about you, Ashley? How, what type of patient were you?

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

Ashley: I found hospitals and especially surgery appointments and cleft clinic days. I found all of those very scary and anxiety-producing really. And so I wanted to know absolutely nothing. So nothing. I, I would make sure that my parents didn't tell me when the surgery was going to be until like maybe a week before because otherwise I would be up all night and it would be all, I would think about all day, every day. I don't know at what age I started to believe this, but I was always certain that the anesthesia was going to kill me and that I was going to die on the table. Okay. And okay, so I would think about the surgery date and think about maybe that's going to be the last day that I'll be alive. I think that was the root of my fear overall mm-hmm <affirmative>. And so even going to the appointments, leading up to a potential surgery, I would leave the room once they started talking about the surgeries and I would, you know, bring my book or I would, you know, sit and close my eyes and plug my ears. And um, I had no desire to know any of it, what was going on. So I definitely found those to be really challenging days and okay. Challenging times for sure.

Iva: I, I want to give you a hug Ash, because it's like, you have to know, but I do understand that I could see essentially if that was your driving fear, you would be like, I don't want to, I don't want to do anything with that. Yeah. So, okay. Well, did you have any kind of weird, crazy contraptions? Cuz I know for myself I had a head of gear that definitely prevented a couple of sleepovers.

Ashley: Yeah. Yeah. I did definitely have some things that they came up with. Um, one of the things was a palate expander, but instead of a key, it was spring loaded. And I think what you just mentioned about having head gear yes. Is sort of one of the pieces of having a cleft that really impacts you socially.

Iva: It does.

Ashley: Cause you look different already and then you miss school for appointments and surgeries. So there's a lot of attention paid to your difference already. Mm-hmm <affirmative> so I'm curious. How do you think having a cleft growing up with a cleft growing up sort of medically needy, how do you think that that impacted you?

Iva: Ooh, the fact the line that you just said about being medically needy, I think is the driving force of me as an adult now not liking to ask for help, not wanting to be seen as, you know, a weak or a victim or yeah. Incapable of things. Like I've just now gotten to a place where I can be okay with asking for help and understanding that it didn't doesn't mean that I'm weak. Yeah. Even when I would have my surgeries and I would have friends come visit or family come visit, there was always a sign on the door that was like, no crying, no sadness. If you were going to come, you had to come in there positively. Um, my mom would get upset with me because I wouldn't take like the pain meds after the surgery. And she was like,

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

you don't have to be brave. You don't have to be brave if you're in pain. It's okay. Yeah. I just, I, I couldn't, I just did not want to be seen in that way. Yeah. Um, yeah.

Ashley: I wonder if then is it hard now because you don't want to be seen as needy or whatever mm-hmm <affirmative> do you find that if you interact with someone who appears more needy in general, does that get on your nerves?

Iva: No, because it's not me <laugh>

Ashley: Oh yeah. OK. OK. I can see that. No, that makes sense. I just was curious if it somehow maybe triggered part in you, you know?

Iva: No. What triggers me is when I feel like I'm being needy like that is when I'm like, okay, Nope. Need to pull back a little bit. Yeah. The funny thing is if someone else is being needy, I'm the first one to help.

Ashley: Hmm. So when I really needed you

Iva: <laugh> yeah,

Ashley: Like was after my jaw surgery. One of the core memories that stands out to me is having a big emotional impact other than just sort of physical pain after jaw surgery. For those of you who don't know mm-hmm <affirmative> uh, your jaw is often wired or rubber-banded shut. So mine was supposed to be wired shut. And then I found out the morning of surgery that there were going to rubber band it. So it's still, I wasn't able to open it at all, but somehow that made me feel relief that it was just rubber banded.

Iva: You were lucky. You were definitely lucky. I, I was wired shut.

Ashley: I still couldn't open my mouth. So it wasn't a matter of luck truly. But what we both had, I know we've talked about this before is the way to feed ourselves. So after jaw surgery, you're on a, on a strictly liquid diet and you have a syringe that holds, it was pretty wide. Mine was pretty wide. And then there was, um, a catheter. So like a very bendy tube. Yes. On the end that was like six inches long. And you would basically stick the tube in, uh, liquid and then you would suck it up. And then you would thread the tube along the outside of your teeth to the back of your mouth where you could push the liquid and swallow it. So I remember after my jaw surgery, it was maybe like five or six days. And I went out to lunch with my mom and my aunt and my cousin.

Ashley: We went to A&W for the explicit reason that there was something there that I would be able to order. So they have this thing called a brown cow, which is

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

basically an ice cream float that is blended together. So I was like, great, this is going to be perfect. And even five days into my six-week liquid diet, I was already starving all of the time. And I walk in and I smell hamburgers and French fries and my stomach's like growling, right? So I get my brown cow drink and I stick the tube in and I go to like, suck up the liquid so I could taste it and

Iva: I can see where this is going.

Ashley: It was too thick and I couldn't suck it up into the tube. And I just started crying. Like I was so hungry and I was so just, I think, emotionally overwhelmed from the full experience. Ugh. That's one of the things that I think back on when I think about really tough parts after surgery and it's little moments like that, you know,

Iva: I can, I can relate. So with my jaw surgery, I, I, mine was wired shut. I think this was one of the very few times that I had a surgery that my mother was concerned because I later found out that she was slipping me Ensure into my chocolate milkshakes, because I was so depressed. Your mouth is truly wired shut and you cannot open it. You can't talk really talk. You can't laugh. And so it's almost like a part of you, especially me. I like to laugh. I like to be very joyful. Yeah. That's gone for a time. And then you also cannot eat food, regular

Ashley: Food. Yes. And the Ensure that you just mentioned, my mom used to sneak it into my milkshakes and I would be like, there is Ensure that you're not drinking this.

Iva: It's obvious that it's in there. And then, you know, my mother would try to be creative and make all these different recipes and it just, it, it was not working. Um <laugh> and so like, Ashley was talking about with the syringe socially, imagine guys going to school and I would have to go into thankfully, Miss Thompson's classroom at lunch. And my friend Kristen was nice enough to come sit with me. Oh. As I'm sitting there trying to suck up my lunch to spur it back <laugh>. But, but you know, and every rough tragedy, there is a moment where you reign victorious. And for me that moment was, it was my sophomore year. And because of the liquid diet, obviously you're going to lose some weight. Mm. So that was the first time. This sounds really bad out loud, but it was the first time that I was able to fit like a size 8 or 10 dress.

Iva: Yes. My doctor had told me that as long as I didn't bump anything and I was, was really careful that I could have it off by the formal dance. Yeah. So I was doing everything that I had to do. I was actually eating because again, I had to be a certain weight too, because he was like, you know, I don't want you to be unhealthy. Mm. So I got it off and I was able to go to the dance and I still have a picture of me in this black, off the shoulder dress. It is a moment that is just, I, I think about it often because I can remember it was like the first time that I felt pretty and gorgeous. Yeah. And I remember like the guys that the dance, mind

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

you they've all seen me before, but they actually looked at me and I felt like they looked at me and didn't see my cleft. They saw me.

Ashley: Did you feel like you had a “She’s All That” moment?

Iva: It was definitely my “She’s All That” moment. It was just, and the funny thing is for anyone who knows me, they know like, I, I love Disney. I'm all about the princess moment. And like, that was the closest that I had ever come to my princess moment. And it was just, it was everything. It was everything. My hair was up and a little up to like I remember that night because I just felt so beautiful all because my, my mouth was wired shut from August to October. That's

Ashley: Amazing. And so you couldn't eat and would be cold. You had your transformation

Iva: Formation. I had my transformation moment. Again, it, it was a black satin ball gown off the shoulder. And that was another big thing because like, normally my mother was like, you can't be doing no, it was off the shoulder with the little shear top. I, when I tell you, I remember this dress because of what it did for me, it, it was more than a dress. It was definitely a transformational moment. Um, my gosh,

Ashley: Did you also feel like transformed because of how you look? Because my jaw surgery, I feel like made almost one of the biggest differences in how I look.

Iva: No. Well, I don't think so at the time, I don't think. Yeah, but you know, let me go back and look at the pictures because I do still have it. So you never know audience, I'll put them up on social media and we can see what, what to say. Yeah. Um, but you know, we can talk forever. We got to go to break. But when we come back, we're going to talk about some of our current struggles that we may be having. Um, so let's go to break.

Speaker 3: We are happy to tell you more about our sponsor: Smile Train. Smile Train pioneered a sustainable model of partnering with local medical professionals in more than 70 countries. In 22 years, it has supported more than 1.5 million safe cleft surgeries, more than all other cleft charities combined. And as many people in our audience know, children born with clefts often need more essential cleft treatments than just surgery. Because their partners provide local, year-round care, Smile Train is also able to fund nutritional support, dental care, orthodontic treatment, speech therapy, and psychosocial support for those who need it. Smile Train invests in their partners, providing them with the state-of-the-art equipment and training they need to make safe and quality care possible for those who need it most. To [smiletrain.org/donate/lovemeetsjoy](https://smiletrain.org/donate/lovemeetsjoy) today and donate \$21 a month to

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

make sure that every child with a cleft can receive the care they need whenever they need it.

Ashley: All right. Welcome back from break. So Iva yes. Feel like we've talked about some sort of heavy things over the last

Iva: Let's let's pull it back. Let's pull it back

Ashley: A little bit. Okay. So now I want to talk about sort of the funny aspects of this whole thing, or

Iva: There's so many, there's so many

Ashley: <laugh>, some of them are funny. Some of them are frustrating, but what I think yeah. Is that they're common for more of us than we even realize.

Iva: Absolutely.

Ashley: So what [00:28:00] is something that you struggle with that you think is because of your cleft?

Iva: So it is not, I it's not that I think I know me and Peppa Pig got one thing in common. We cannot whistle and I am very upset about it. Okay. <laugh> I am very upset about it. And the fact that other people are whistling really does bother me <laugh> and when I was growing up, I struggled to be able to like blow a bubble to the point that I would have. It's kind of nice, nasty, sorry, audience, but I would have my mom start the bubble and then I would take it. Yeah. So I, so I could feel like I blew a bubble, but I can blow my own bubbles. Now guys, I can blow my own bubbles now,

Ashley: But I remember my mom doing that with balloons for me because sometimes like I got to a point where I could blow it up, but it had to be like really stretched out first. So sometimes I would have her blow it up first and then I would be able to blow it up or she would start it. Right. And she would also start my milkshakes, like when we would go to McDonald's and I would get a milkshake, it would be too thick for me to suck it in the straw by myself. But once it got started, then I was able to actually drink it. So <laugh>, and that

Iva: Is something that's fairly, that is very common in the cleft community. For those of us who, you know, are missing parts of our, our palate. Like again guys, yes. You don't realize it until you don't have something, but that is very important. And then also, do you ever have food come out of your nose? Like pasta

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

- Ashley: <laugh> um, so you have mentioned like long spaghetti noodles before, and I have not ever had pasta, but I have had like rice and if it's like spicy, because if there's siracha or something on it, like it makes me want to cry. Like it's terrible. So
- Iva: I've never had rice, but definitely pasta. I figured that out on a date and oh no, I'm not going to get, yeah, that was great. I'm not going to get into too much detail, but sometimes throwing up is not fun.
- Ashley: Yes. No. Oh my goodness. I definitely know what you're talking about. And then do you ever, um, when you eat popcorn and little kernels somehow flip the wrong way and get stuck in your palate scars?
- Iva: Yes. Yep.
- Ashley: Does that happen?
- Iva: Yes. And you have to fight to try to get it out. Yeah.
- Ashley: Oh, it is just the worst. And some of these things were worse prior to our bone graft surgeries, because we still had the hole in our mouths. Like I think some people don't realize that when, you know, you have palate repair, but for a lot of us, there's still something there. Correct. So it makes it challenging for, you know, blowing up bubbles, blowing up balloons, doing all of those things. For sure.
- Iva: Most of us have our bone graft surgery at the age of 10. So that's a long time to be living for sure. <laugh> like that.
- Ashley: So that one kind of like came in the middle of my cleft surgeries. What was your last or most recent cleft surgery?
- Iva: My last surgery was, and it was so a part of my cleft, uh, was my rhinoplasty. That was my last one.
- Ashley: Me too. Me too.
- Iva: That was my last one. Um, yeah. And it's funny because that last one was the hardest one.
- Ashley: Oh really? That's interesting.
- Iva: I was 21 right after college and I was like, okay, this is going to be the one because I had gone to a new plastic surgeon this time. So I just knew that this is going to be the, the magic eraser one. Right. Everything's going to be right after

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

this one. Yes. And all it all. He did a great job. Um, because yeah, again, as we often mention me being an African American woman, he was very, you know, poignant to make sure that my nose, um, fit for my, for my aesthetic. And he did a great job of that. That's something that I was always very keen on. Like, but the cleft was still there and it was in that surgery that I had to face up and realize, Hey, you can't outrun this cleft. You're going to always have a cleft it was sad and good at the same time.

Ashley: Hmm. I had almost the exact same experience, but when I had mine done, I was 30. So I remember it was put on the table when I was about 18. And I was like, no more surgeries. I'm done. I'm over this. I'm happy the way I am. And that's an important part of this journey as well, because I think at 18 I reached a certain level of acceptance. And then when I was 30 and I decided that I actually was kind of interested in pursuing this rhinoplasty. I sort of had a, a conflicting piece inside of me because then I wondered if the last 10 years I'd been lying to myself or whatever. But so I went ahead with it and similar to you, I was certain afterward, everyone was going to be like, wow, you look amazing. Like

Iva: Who's that person? Yeah.

Ashley: I thought like maybe people wouldn't stare at me anymore. And, and I remember, I didn't tell hardly anyone I was doing it. And then when I started seeing my friends afterwards, I was like, all right, they're going to say something, you know, <laugh> and literally nobody did. And the only comment that I did get was one person asked me if I had lost weight so they could tell something was different, but it wasn't my nose. And no one was like, your face is so gorgeous. You know?

Iva: Exactly. It is a hurtful thing. Cause it's just like we had this idea. Um, and so you just have to, that self-acceptance was a hard one.

Ashley: It is hard. And I think it was this moment of trying to figure out when I was going to be done. You know what I mean? Yeah. Actually I had surgery scheduled for maybe six months after my rhinoplasty. I was going to have a graft in my upper lip. Really mm-hmm <affirmative> yeah. Cause it tugs up in the middle because over time the scars have contracted and okay. Really what they would normally do for that is the ABB flap surgery. Uh okay. But in the recovery they sew your lips together and I just was not about that life. And so I was like a graft. I'm going to do that. So I actually had it scheduled and then I ended up getting a cold. So the week before surgery or something, I canceled it. Okay. And I never ended up rescheduling it, but it was because I've, I've sort of had this struggle inside of me trying to figure out mm-hmm <affirmative> so I do the graft and then what, you know, cause

Iva: You're going to always be looking. Yeah.

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

- Ashley: Yeah. And so it was sort of, then that I realized that it was sort of this inside job that I was mm-hmm <affirmative> it wasn't this external something that was going to give me the acceptance I'd been looking for,
- Iva: Do what you need to do to make yourself feel good and feel beautiful, but you have to understand that perfection is not obtainable. Like, and that's something that that's where I'm at now. And so I'm very happy where I'm at now, but it's because as we've always talking about, I've done the inside work and I'm actually proud to say that I am a cleft affected woman. Just like I'm proud to say I'm a black woman. I'm proud to say that I'm a cleft affected woman. And so I don't want to hide it anymore. Um, like we, we were talking about our bone graft and most cleft affected people. They have a bone graft scar mm-hmm <affirmative> and mine was like kind of fading away for a while. And I was upset. I didn't want it to go
- Ashley: It's on the hip for people who don't know the bone graft is where they take a piece of your bone marrow or bone from your hip because where the cleft is in your mouth, there's a gap in the gum. Like there's no bone there. And so, and
- Iva: They meld together.
- Ashley: Yes. And so then it makes it so that our teeth are more solid.
- Iva: Yeah. And so it's kind of like a badge of honor that most of us have and because mine was fading away, I was really getting sad because to me it's like, it's a testament to what I've gone through. And it's, it's a part of, it's a part of me and I don't want it to leave me.. Yeah. Full circle.
- Ashley: I think that's such a really important and powerful note for us to end on that. Perfection is unattainable and also that the acceptance of who we are had to truly come from within ourselves
- Iva: Yes.
- Ashley: Over anything external that we could do to our faces or bodies.
- Iva: So yeah, exactly. Cuz what's in, you always comes out. And so the more that we can pour in that love and that joy, we got it well everyone that is our chat for today. Thank you so much for listening as always. We'd love to hear from you. What was your journey like? Please email us at [lovemeetsjoy@smiletrain.org](mailto:lovemeetsjoy@smiletrain.org). And you can find me on Instagram and TikTok at RealSophisticatedJoy.
- Ashley: And you can find me on Instagram at CleftLove IG or on TikTok at Cleft Love. And don't forget to go to [smiletrain.org](http://smiletrain.org) to learn more about all the wonderful and

Love Meets Joy Podcast  
Episode 2: Our Cleft Journeys  
Transcript

amazing things. Smile Train is doing for the cleft community around the world. You can find us on your favorite podcast streaming site. And while you're there, please don't forget to leave us a five-star review.

Iva: Yes. All right, everyone. Bye. See you next week.

Ashley: Bye.

Speaker 3: If you like this show, be sure to subscribe, leave a review, follow us on social and tell all of your friends to listen. Please reach out with any questions or episode ideas by emailing us at [lovemeetsjoy@smiletrain.org](mailto:lovemeetsjoy@smiletrain.org). We can't wait to hear from you. Love Meets Joy is a product of Smile Train. Our hosts are Iva and Ashley. Our Senior Producer and Editor is Ariel Nachman. Our Smile Train Producer is Adina Lescher. Love Meets Joy is presented by Smile Train the world's largest cleft focused organization. One in 700 babies is born with a cleft, a potentially life threatening birth difference that can cause difficulties eating, breathing, hearing, and speaking. The good news is that Smile Train developed a sustainable model that empowers local healthcare workers around the world to provide lifesaving cleft treatment, to all who need it everywhere on earth 100% free. Learn more at [smiletrain.org](http://smiletrain.org). The information provided in these recordings is meant to be helpful to you and is provided as is for informational purposes. Smile Train cannot guarantee it is accurate up to date or error-free. We are not responsible for the content and disclaim all liability concerning actions taken or not taken based on these recordings.