

Love Meets Joy Podcast  
Season 2 Episode 5  
*The Cleft Journey of a Sibling: Meet Isaac Ballou and Michael Barbour*  
Transcript

- Iva Ballou: Hey everyone. Welcome to the Love Meets Joy podcast on the Smile Train podcast network. I'm Iva Ballou. I was born with a bilateral cleft lip and palate. I'm the Smile Train Cleft Community Development anager, the CEO of Real Sophisticated Joy and a cleft confidence coach.
- Ashley Barbour: And I'm Ashley Barbour. I was also born with a bilateral cleft lip and palate. I'm the creator of Cleft Love where I share my journey of self-acceptance and spread awareness of cleft. And today I'm so excited for this incredibly special episode. So last season, many of you might remember that Iva and I had a special opportunity to interview our moms, and today we get to interview our brothers.
- Iva: Yes, Ashley. And something that's really interesting guys, is that we both have brothers. My brother is five years older and Ashley's brother is five years younger. And so we're going to talk about what our journey has been, not just what our journey has been, but their journey. They went along this cleft journey with us. So I'm really excited to hear their perspective.
- Ashley: Yes, and I feel like the perspective that's often lost is the sibling perspective because when you have a child who has special needs, that child is focused on so much. And so I think it's really important to note that this is the only organization that's talking about this right now. And I just think it's super special that both Isaac and Michael are here today. And so when we come back, we'll be joined by Iva's Brother Isaac.
- Iva: Yes. You guys get to meet my older brother Isaac. I'm so excited to have him here today. So first off, Isaac, thank you so much for joining.
- Isaac Ballou: Thank you for having me.
- Iva: For those who don't know, he's my older brother by five years. He's a loving husband, he is a hardworking dad. So we're just happy to have you.
- Isaac: I will fit you in my busy calendar anytime. I've been here for the journey, so I'm not going to stop now. And not that you would let me shirk my big brother duties.

Iva: Of course not. Of course not. And being that you are my big brother, do you remember when you first learned that one, you were having a sister, but that sister was going to be born with something that made her different?

Isaac: So I personally think I asked for a little brother, but my mom, mom, clearly says that I asked for a little sister, but I do remember asking for a little sibling to have around because everybody else had siblings, and I just wanted to feel like I was included with that. Unfortunately, I don't think I was explained early on what issues that you would be facing through your birth and through your development and all of that. I didn't really get an explanation until you were here. And then it's just like, well, I don't remember you being any different. I just remember you being my sister and being protective and often telling mom, don't worry, I got this.

Iva: Our mom loves to tell the story about how when I was six weeks old, Isaac picked me up out of my crib and was trying to care for me saying, come on, baby sister mama doesn't know anything about taking care of a baby. And so I wonder, do you think that maybe, although it wasn't communicated that there was something different about me in your little five-year-old self, you knew something was going on?

Isaac: There had to have been something within that five-year-old brain that just knew that you were special and that needed to be protected differently. We didn't have an extreme amount of family growing up in Jacksonville, so it wasn't like that I was around a lot of little babies to have that innate responsibility already. But for whatever reason, I just knew I was supposed to try to protect you in that moment. I don't know what I was protecting you from. I just know I needed to do it.

Iva: So you've always been a protector of mine and the advocate for me. Do you think that by being my big brother, that was something that you kind of grew into, not just with me but just in your life?

Isaac: It definitely started shaping the person that I grew up in. We came from a generation where there weren't participation trophies. You still got picked on in school for the right reasons and sometimes the wrong reasons. And so it definitely shaped my mind about how I approached dealing with other kids because I remember absolutely going into shopping centers, going out to the doctors, even just going out and just even sometimes to church, just the way that you would get looks that I didn't always understand initially. But the older I got, the more I was uncomfortable about if you want to look, you can say something and if you don't know what to say, ask a question. It kind of put a chip on my shoulder. I mean, I have to defend the people who can't defend

themselves, and that's kind of who I am today. There's a level of what's right is right. What's wrong is wrong, but you're going to treat people the way they're supposed to be treated. And everybody deserves the rights to be treated fairly and equitably. And that's one of those things that because of our experiences going through life, that's kind of how it shaped me to the young man to now the younger older man, because I'm not going to call myself old, but the younger older man and who's raising kids,

Iva : You're not old. You're not old.

Isaac: I want them to still have that same belief that you have to fight for the people who can't fight for themselves.

Iva: So you've been an advocate for our community before you even knew it.

Isaac: Before I knew that was a thing.

Iva: I can remember a couple of times of you getting into altercations with people just because they may have said something. And at first I will say thank you for just always being my protector. Something that you mentioned earlier was that it wasn't fully explained to you. So another thing is the summertime, because I had most of my surgeries during the summertime and we had talked about it. You made a good point that you were never there for my surgeries. And so we had to have the question of where did you go?

Isaac: I'd never, you would tell me stories about, oh, I had this surgery and this surgery and that surgery. They'll be like, when did you have that surgery? What did I miss? I don't think the first surgery that I really recognized was not until you had one of your hip ones, you had to have a graft. And that was one of, but that was well down the road. I had to go back and ask mom, where was it? Why don't I remember that? And it was at the time, I'm thinking that I'm going to grandparents and family's house just to spend time with them because they lived in North Carolina, we lived in Florida. So trying to have that relationship, I thought that's what I was going for. Not recognizing that it was really, Hey, we need to spend this time focused on Iva. Isaac through no fault of your own, you're going to get in the way. You're not really helpful in this space, so now we're going to need you to go be with other people so we can take care of this. But that wasn't explained there. We've talked about there wasn't the understanding and the appreciation for what was actually transpiring until well after the fact.

Iva: Yeah, because the term that came up that you initially said, the first time that we talked about, it's like that you got shipped off and you didn't understand why you got shipped off. And I didn't and I was like, I want to go too.

Isaac: It wasn't until I was older, it started reconciling the things that happened. It's like it was a shipped off. Yes. The packaging presented itself like, Hey, you can go to spend time with your cousins who are a similar age. So of course to me it didn't feel like a shipped off in the moment. But when you look back, it was clearly it shipped off because there was no communication about why outside of the illusion of it just being about family.

Iva : Because in that same sense of family, we kind of grew up in the same household but had different upbringings. That's something that we also kind of struggled about. My cleft journey and then your cleft journey with me is that mainly like dad, our dad who has passed away, you would say it was a lot more caring and nurturing towards me compared to you. And it was more than just because I was a girl. It was because I was different

Isaac: And I didn't understand that it was because you were different at that time. The way dad presented it was very much, you're a boy, she's a girl. You can't do what she does. She can't do what you does, and I don't care if she punches you, kicks you, steps on you, whatever. You can't do anything in return to retaliate to her. And it was at the time, it's not understanding that it wasn't just because you are a girl, it was because you also had your other things going on with your cleft that he was trying to protect you from that. And so in my mind it was, well, she could just do whatever she want to do when it comes to messing with me, but why are there restrictions on my life that I can't do the same and we're supposed to be fair? Because fairness was always talked about that if it's good for the goose, it's good for the gander. Every anecdote that you want to use for a parent telling you why they can do something, you can't do it. We had. And so coming up and growing with that, it definitely took its toll to try to understand what's acceptable behavior and what's not, and life isn't fair, but at the same time, life isn't fair so you can learn the lessons.

Iva: So along with that, it would also be not just our upbringing in that way, but our attitudes. Because something that you always, and I thank you. I will say here, I thank you for being a mirror to me a lot of times of just because you have this thing does not mean that you can just act out. Because I was angry, especially after dad died. I was extremely angry and just wasn't kind. It wasn't nice. Something that I've talked about on the podcast before, but you were definitely a mirror saying, hey!

Isaac: You were a diva. Let's be exact. You were a bona fide diva.

Iva: I was

Isaac: There were times where I specifically remember situations where you made no doubts about it, that you didn't have to do this because my name is Iva and I don't do those type of things. And I would just look at mom and others and be like, y'all just going to roll with this. If I had that attitude, it would've been a completely different situation. And so it wasn't until I got older and our relationship started changing that I could truly, like you said, be your mirror and be like, Hey, you can't ask for something that you're not willing to give. Because there were a lot of times that your frustration and anger caused you more stress and frustration because you wanted to control every aspect of your life because you wanted to quote - unquote take your power back. But the way you were going about trying to take your power back just made parts of the way you presented yourself, not the person that I knew you were. More than that you ain't no kid no more. I don't have to take this anymore. And so a large part of it was not just for my own self-preservation, but it was preservation for you. I know I had to leave the house and go start my own life. I needed to make sure that you were, especially after dad died, prepared to face a world that I'm not always going to be a part of that isn't always going to protect you in the same manner that he or I would do for you. So you have to start changing the way you approach life to make it better for yourself in a sense that you don't want to have to fight with people that you don't have to fight.

Iva: And I thank you for that. I've never said it, but see, it's on record. Thank you. But you mentioned taking my power back.

Isaac: Can I get a copy of the recording?

Iva: Anyway? You mentioned taking my power back and I did that the first, my step toward that I would say would be the first time that I posted my baby picture. And I can remember you were really shocked.

Isaac: I was.

Iva: Why were you shocked?

Isaac: Because that was something that you made no qualms about through most of our childhood teenage years, young adult years, that you didn't want that person to exist. And it was like, I don't understand why you didn't want that person to exist, because you can't know where you're going if you don't know where you came from. When I saw you finally put that up, I was able to truly see that you're finally understanding who you are and the growth that comes with that. It takes a lot of internal strength to be able to be that vulnerable. And there's people who have never faced some of the challenges that you have who will still never be that vulnerable. Being able to witness the growth in

that and being willing, being willing to share. I couldn't do anything but take my hat off. And that was one of the most proudest moments that I had of you for truly being able to sit in your own skin and embrace who you actually are.

Iva: We have made a promise to each other that we weren't going to cry. That's out the window, guys. But-

Isaac: I kept mine.

Iva: Shut up. Now that you have witnessed my growth, do you still feel the need to protect me?

Isaac: Of course. I'll always, because you are my little sister by my upbringing and indoctrination by dad, there's no way I would never protect you. However, that protection looks a lot different than it used to. I don't feel like I need to be your dominant male physical protector anymore. I'm more of a mentor, person to bounce ideas off of, person who's going to hold you accountable to the things that you are holding yourself to. So, my protection looks different, but it's very much the same

Iva: And speaking of the protection looking different because part of that, and again, that was something that was hard for me to release, is now you have little ones to protect yourself. And how has your upbringing with having a cleft affected the sister affected you with your girls? Because I have to tell you something that I realized in the making of this podcast. I used to be really nervous before when you were finding out that 20 weeks if they would be cleft affected. I don't know if I ever told you that.

Isaac: I don't ever know if I told you that. Me and Charity every time it was part of the conversation because I felt like we had to ask this question because when they do the family background period, that's not part of the questioning that they ask. And it's like, why is it not part of the questioning? So now it's like, okay, well hey, just for the record, this is part of my familial background. This is something that can occur. Okay, noted. And they'll leave it at that. So it's just like that's weird. I felt like there should be a stronger support for that, at least in the diagnosing early in the pregnancy process. But once they were here and trying to just raise beautiful young women, try to give them the confidence is just something that's having watched your struggle and it taking time and just seeing how life has used social media in a way to warp individual's perception of that. In some cases, I really do try hard to get them to see and look within themselves to say, Hey, you are beautiful. Not just because of your outside, but who you are as a person. That's really what I try to instill each of my girls, even my son. I try to let him know that it's

important to look within and be proud of yourself from who you are, and then the rest of it will follow

Iva: And with the rest of it following. Have you ever had to have the conversation about my cleft with your kids?

Isaac: Yes. I had to have a conversation with my son the other, a while back before the holidays because he got into an issue at school when it was, I wouldn't quote unquote call it bullying, but it was definitely making fun of somebody because of a physical attribute. And I had to let him know. I'm like, dude, you're comfortable talking about somebody, but you don't understand that to me, that feels like you're talking about my sister. And how would you feel if somebody talked about your aunt? And he was like, well, I wouldn't like it. I was like, but that's what you're doing to somebody else's child, sibling brother, sister. Be cognizant of how you address people and how you make them feel because those are the things that are going to show up in life and you don't want to feel like that. So you shouldn't lead like that whether you're sitting around other people, you shouldn't be comfortable allowing people to talk about people like that in your presence. It's your responsibility to hold other men and other people accountable to being their best selves.

Iva: Beautiful. Making me proud. Before we go, one last thought. Do you have anything that you would like to share to any siblings out there or to parents who have a cleft affected child and a non cleft affected child?

Isaac: Yeah, I will address both to the parents. Please take the time to truly embrace all of your children into the process of what it takes and what your child is going through. Because not addressing the non cleft affected child can sometimes build resentment, can sometimes build repressed feelings because they feel like they're the outcast, not by design, just by the unintended consequences of the process, though the cleft child is going to get more because they need more, and there's nothing wrong with that, but that conversation needs to be had so everybody can be on the same page so people don't grow up with a sense of loneliness just because they weren't included with certain decisions. And for the siblings, I would just say continue to embrace this journey, continue to embrace your cleft affected siblings' path. It's not going to be straightforward. It's not going to always be easy and just be willing to be a voice, be willing to be a shoulder to lean on. Just accept who they are and just let them know that I'm not going to go anywhere. If you have, regardless of what the world's going to do, you have one person who's going to be in your corner, who's going to help you fight the world if that's what we need to do. But you have to be in this together. And I'll tell the cleft

affected sibling, be willing to share, be willing to be vulnerable. And you never know what could actually happen if you lead with your ability to show, Hey, this is what I need, this is what I'm struggling with, and this is how you can support me moving forward.

Iva : Beautiful. Well, Isaac, that is our time. I want to thank you for coming on the podcast, and thank you for being my big brother. You are awesome at that job. And now we're going to hear from our sponsors, and when we come back, we'll hear from Ashley and her brother Michael. Thank you Isaac for being here.

Isaac: Thank you guys for having me.

Announcer: We are happy to tell you more about our sponsor. Smile Train. Smile Train pioneered a sustainable model of partnering with local media professionals in more than 70 countries. Since 1999, 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 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. But this isn't possible without your support. Go to [smiletrain.org/donate/lovemeetsjoy](https://smiletrain.org/donate/lovemeetsjoy) today and donate \$21 a month to make sure that every child with a cleft can receive the care they need whenever they need it. That's [smiletrain.org/donate/lovemeetsjoy](https://smiletrain.org/donate/lovemeetsjoy).

Ashley: Welcome back everyone. I certainly enjoyed listening to Iva and Isaac have their conversation. And now I want to introduce everyone to our next guest, my brother Michael. And I'm really excited to have this conversation because you and I haven't really talked about any of this before. So Michael, thank you so much for being here.

Michael: Thank you so much for having me. I'm really excited to be here.

Ashley: So something that's really interesting is that Iva's brother is five years older and you're five years younger than me. And even though I was only five when you were born, I remember so much about that day. So I was in aftercare and it was Fort Day, which was once a week. We were allowed to use nap mats to make forts. And so I was crawling out of the fort, and I remember one of the childcare workers came over and she was like, Ashley, your dad's here and he has a surprise for you. And I was like, oh, what is it? And dad came over and

he was like, you have a new brother. Do you want to go meet him? And I was like, yes, I do. And so we went and I just remember getting to hold you and feeling so proud of you and proud to be your sister. So I don't know if I've ever even told you that before. Have you heard that story before?

Michael: I think so. I feel like I definitely associate Fort Day with it. That was still going when I went there. Yeah, when I was in Aftercare, they were still rolling Fort Day. So there's a tie between that or at least aftercare with when dad told you

Ashley: It was a very special day because it was Fort Day and there was a baby brother, so-

Michael: It's true. And Fort Day was Friday, so it was a Friday too.

Ashley: I think it was a Friday. I know. Yeah. All the good things. Since you were younger, you were only alive for a few of my surgeries, so I'm curious what you remember about any of them or which ones you remember or any of that.

Michael: I think the only one that I actively remember that I was here for was the jaw surgery.

Ashley: Yeah.

Michael: What was the time period before the jaw surgery? I don't know that there was...

Ashley: Yeah, the one before that would've been my bone graft and I would've been eight. So you would've been like three-ish. So you probably don't have any memory of that. And so for my jaw surgery, do you remember, did you go to grandma's house?

Michael: Probably? You were 16?

Ashley: Yeah, 15.

Michael: 15, okay. So I would've been 10. Yeah. So I feel like I probably went to grandma's and then I definitely came up to visit you at the hospital at some point. I remember your room. That was the Easter one. That was the Peter Cottontail?

Ashley: Yes.

Michael: Did you get that stuffed animal then?

Ashley: I did, yeah. The one that sang. Yeah. Sang Peter Cottontail. Yeah.

Michael: Yeah. So I remember that. Yeah.

Ashley: Do you remember afterward? I know that I slept on the pullout couch downstairs with mom for a while, and I was sleeping all the time cause of the pain medicine they had me on. Do you remember all of us piling into the pullout sofa and watching movies? That's something that I definitely remember, and it was so nice to feel, so I don't know, supported by everyone, because you were all there with me, so- Something else that I remember you and I used to do a lot as kids is we would go through our photo albums and stuff, and I'm curious if you ever remember noticing that my baby pictures were different because I have been asked that by parents before, not necessarily about siblings, but about my own, how much I remember was there a day that I saw my baby picture and I realized it was different, or was there a time that I looked in the mirror and I realized that I was different? And I have a really hard time pinpointing everything because I feel like the baby pictures were always just there and available, and it's not like there was any huge conversation around it. And so I am interested to know if your experience was similar or if there was a moment where you realized that I was different.

Michael: It was one of those things where pictures just always were around, and I think it was just something that was talked about at least as openly as you were. Mom and dad were very open.

Ashley: Yes.

Michael: With photos. I really don't know that there was a defining moment. Yeah.

Ashley: Yeah. It was just me.

Michael: Yeah. Yeah, it was just, oh yeah, those are baby pictures. And then there were some surgeries and it was Ashley. It was, yeah.

Ashley: So you growing up always were just like, oh, this is Ashley. And then was there ever an experience in your life where somebody called attention to it and then that made think differently about it, or maybe not think differently about it, but just called your attention to it?

Michael: Not often, but there are a couple of times I can pinpoint that there were kids or a kid with siblings in your grade that needed to tease somebody about something

Ashley: And so they teased you about me?

Michael: Yeah. It was like teasing you to me. Like, teasing me by proxy.

Ashley: So what did they say?

Michael: I feel like it was doing maybe gestures about your nose being flat, and it was probably elementary school, so in the way that elementary schoolers are elementary schoolers. It was interesting. I was angry about it, but I was also very, I was like, what are you talking about? Or when you've talked about your scar, I don't know how old I was when I first was even able to be like-

Ashley: Right! Like, you didn't even see it. People on the podcast know that my strategy for dealing with any sort of teasing was just to totally ignore it, and it kind of went away. And so did you, did you do anything or did you not feel like you had to do anything, or did it make you feel like you had to protect me in some way?

Michael: I don't specifically remember, but knowing the feelings associated with it and knowing me as a person, I imagine I had a fairly large reaction to it in some form of heightened trying to get someone to stop something that was making me annoyed

Ashley: Right. That maybe wasn't super effective, maybe,

Michael: Maybe led to more of the same, maybe it was a little provocative. Yeah, so I think it probably got worked up and it was fuel to the fire more than anything. But yeah, it was definitely a sense of protecting and reacting based in discomfort of not really fully understanding everything too, I think.

Ashley: Yeah. No, that makes a lot of sense. It's interesting to hear you talk about some of these things because I think, I don't know, in part it's because we haven't talked about it. It can be hard to pinpoint certain answers, and I feel like that sort of reflects my own journey with cleft and my own experience with it, because for so long it just wasn't something that I thought about. It was just part of my life. Now I've done a lot of therapy and a lot of stuff like that that has caused me to really examine how it might've actually impacted me. And so I'm starting to see that certain things were actually bigger than I thought. I'm curious though, as a younger sibling, we went to all the same schools. You were always a handful of grades behind me in school and just existing in the same house, because I know in some ways you and I are very different, and so I'm just interested to know what that experience was like for you,

Michael: Hearing you describe that kind of drive to be quote unquote perfect at everything, that kind of camouflage. I think I was always feeling a little bit like I was underperforming kind of in your shadow a little bit. It wasn't something that I was able to really put my finger on until I was much older. When you talked about therapy, you find all kinds of things. I feel like maybe

I always had kind of a drive to get that from mom and dad. You did a good job with that camouflage. It always felt like you were very good at everything, and I was always trying and just it felt like I couldn't quite get there.

Ashley: Yeah. So it sounds like then it was challenging because I was the first one who had gone through all the school and all the whatever, and then you were coming up behind me, and then it felt like because I was overperforming, then mom and dad were like, why aren't you overperforming? Or why aren't you?

Michael: Yeah, this scale was a little, felt a little skewed, whether reality or not where I was at with the facilities I had, that was, yeah.

Ashley: Yeah, it just felt a lot harder. It used to drive me nuts that I felt like you got more leniency. So I knew that I followed the rules and I got good grades, and I did all these things. So you would think that that would earn me more privileges or something. But no, that was not the case. And in fact, I used to just feel like, gosh, I don't know what else I can do to be better to earn these privileges. An example is I had a curfew, a midnight curfew through college, not while I was obviously at school. They weren't there, but I would come home for breaks and I would want to go out to the club with my friends or whatever, and I would have to be home by midnight. But then when you came along, you just had a note card that you had to put in the bathroom when you got home just to be like, oh, I'm home. And I would be like, ah. So I don't know if it's like you were a boy and maybe you were younger, so they were just tired by that time around or what I want to do,

Michael: One of the thoughts that comes to my mind, I'm sure it's multifaceted, but did you ever challenge it,

Ashley: Right? Oh, there is that there is that.

Michael: I feel like mom probably was pushing it and I was like, no, I'm going to go out. And she was like, fine, leave a note card. And that's how the note card was born. So I feel like maybe yes, and-

Ashley: I just didn't push it enough. Oh, see?

Michael: I was a little bit of a boundary pusher. I don't know, maybe that was-

Ashley: Maybe that was part of it for sure,

Michael: From my perspective. And I think it was just because you were such a rule abider, it seemed like you got a lot more leniency. It felt like from seventh grade till I graduated high school, there was some level of mom and dad either

being frustrated or exhausted or some other feeling to me that I just couldn't quite escape. So it's really interesting to hear

Ashley: From my perspective, it felt like I had all these rules and I wasn't allowed to do any of these things. You said that it felt like there was an element of protectiveness, and that was something that was different in the relationships in your perception.

Michael: Yeah. It did feel like there was, you went through a lot and was you went through a lot. It felt like I was sometimes missing a piece because I didn't go through that with you guys, which is a weird, complex, complicated thing in and of itself. Yeah. There was this piece of the story that I missed out on sometimes, I guess is kind of the that or missing out on

Ashley: The bonding or something.

Michael: I think some level of bonding that happened through all of that.

Ashley: And then it was hard to break through or break into that.

Michael: Yeah. Yeah. Felt a little bit outside of it sometimes, I guess.

Ashley: Yeah. I imagine as a parent, when you have a baby that's born with a difference and they have to do all these medical interventions and things like that, there's an element of needing to be protective and needing to pay extra close attention to them. I have a feeling that there are other siblings that that story will resonate with as well. I'm glad that you shared that for sure.

Michael: Mom and dad did so much to not have that. There was so much of trying to put us on an even keel or think about how I used to get birthday presents on your birthday,

Ashley: Which I did not get birthday presents on your birthday. Let me just say. Although they didn't come from mom and dad, they came from grandparents and stuff. I don't think mom and dad actually got you presents.

Michael: That makes sense. Spoiled rotten.

Ashley: Yeah. Let's talk about the unevenness some more. And the leniency that you have

Michael: Again, did you challenge it? Did you challenge, I want presents on his birthday too. That might be the difference. Again.

Ashley: They probably did, and they were just like, you're older, you're fine,

Michael: You're fine.

Ashley: It's like that perception thing. So it sounds like there were times that you felt left out because you weren't bonded in this experience, which I can totally imagine and see how that is. But I remember watching a show a few years ago, it was a docu-series or a documentary about a boy who was born with Treacher Collins, which is a pretty significant facial difference. It's what the boy who is in Wonder was born with, and the boys' parents came on the screen and they were talking about their experience, and I remember them saying that they wanted to have another baby after the first one was born because the first one had Treacher Collins. They wanted to have a second baby so that they could have a normal experience, like a normal baby. And then I just remember being like, oh my God, I never thought about that. Put words to that before. Parents are obviously entitled to have whatever feelings that they're having, but I remember that really threw me because it was never something that I thought of and that I was like, oh my gosh, what if I wasn't enough? I feel like so much, so many of the experiences with cleft when you're trying to get treated and let's do this and we'll do a little bit more to make you a little bit better, and all of these things point to you not being enough. So then when I heard that story on that show, I remember just being kind of devastated. And this was only a few years ago, but anyway, it's just interesting. That would be another side of things you felt outside of it. But then now I always have this thought in my head that I wasn't what they envisioned, and so they wanted another baby to be what they did.

Michael: Yeah, yeah,

Ashley: Yeah. Just an interesting perspective thing, right?

Michael: Perspectives and the way that things can kind of look or get into our heads or those perspective shifts

Ashley: And that we all are having such a unique experience in the growing up process. And so talking about things even more would have probably been better. Not that it was ever hidden or anything, but so when I started sharing my story publicly, it was, did you ever have any negative feelings or embarrassment or anything like that?

Michael: No. It was all overwhelmingly positive, really just with the lens of really seeing all the levels and perspectives and dynamics of your experience. There was never any negative feelings, really just proud and happy and interested, I guess.

Ashley: So I do just want to end. We are running out of time, but I just want to end with a story that I also don't know that I have ever told you. So when I was

seven or eight, I remember I was overcome with emotion and I didn't know how to name the feeling that I was feeling. And so it was about you. And I went to talk to mom, and I was like, mom, I'm having this feeling right now, and I don't know what it is. I really, really want to give Michael a Barbie or one of my toys or something like that, but I know that he won't like it, but I just desperately want to give him something. And she just looked at me and she said, that's what love feels like. That's what she said. And so anyway, thank you for helping to teach me what love is, and I am so grateful for you and for you being willing to come on this. These are conversations that many siblings haven't even talked about behind closed doors, and so I'm just so grateful that you are willing to come on here and do it publicly. And so I appreciate your vulnerability and you.

Michael: I appreciate you. Well, thank you very much for having me again. This was really nice.

Ashley: And Iva and I can't wait to chat about this conversation and her conversation with Isaac. And so when we come back, we'll have our wrap up.

Iva: Thank you so much, Michael. That was awesome. And I was so glad to listen and hear that. And I know the audience loved it as well. There are so many times listening that I was just like, I feel you younger brother. So younger brothers, the younger siblings unite on that one. So guys, we're going to, for this next part, we're going to talk about just and reflect on what our brothers said and what that meant for us. So I don't know, Ashley. It was a lot. I think we learned a lot.

Ashley: We learned a lot. I absolutely loved getting to meet your brother and listen to that conversation between the two of you. Again, I feel like we've said this several times, but these conversations are so important to have. And I think in a lot of households, mine included, anyway, it wasn't a conversation that we ever had. We didn't include it in there, but I have to tell you that one of my favorite things that your brother talked about was when you asked him how he felt when you first shared your baby picture publicly, he was surprised because when you were younger, you wanted nothing to do with how you used to look. And so it showed a big step forward and maybe a step towards accepting who you are. And probably my favorite thing that he said was, he was so proud of you for doing that and for recognizing that as part of your story and part of your journey, because he said, you don't know where you're going if you don't know where you came from. I just thought that was a really beautiful thing.

Iva: I have to admit, I related to Michael the entire time the audience couldn't see, but I was cheering him on. I was like, yes, again. But there was a couple of things that he said. The first would be one of the very last things that he said of you're putting good healing out into the world, but you're also bringing it on the inside. And I think that just speaks to, again, we're doing this, but we're still growing too. And so the fact that he had this resounding like, no, I was so happy that you were doing this, and yes, he's your younger brother, but he's still your brother. And he was like, yeah, you were just Ashley, and he was so proud to see you do that and to make your space I thought was beautiful. And then something else that caught me was, again, we've talked about this in season one of the story that you tell,

Ashley: Yes

Iva: He was telling himself, and I'm pretty sure a lot of siblings are out there telling the story of, it's team mom and dad and cleft affected sibling. And I'm out here. And it's like, well, maybe if we have certain conversations, we can see that there's no, we're in this together. No one's on the outside. I have my experience. You have your experience, but we're still siblings. And I thought that was really beautiful that he would be vulnerable and open that up. It was beautiful.

Ashley: Something that was so cool about this episode was getting to hear from an older brother perspective and a younger brother perspective. One other sort of similar thing was, even though your brother was older, I expected him to have a lot of memories about your surgeries and recovery and all of that. And he didn't. I mean, some of that was because he was gone or whatever, but he said something like, he missed what was happening. Why don't I remember? And it's so interesting that that was a parallel in their stories because that was surprising to me. I didn't expect that.

Iva: And because Michael said the same thing about I wasn't there, I wasn't there, so he didn't, and then something else that he said was sometimes we look at it like, oh, that was a cleft thing that I didn't get to do that, or I get to do that. Or My parents treated me this way of talking about the leniency. And it's like maybe it was because he was a boy that he had no curfew. Again, Isaac had no curfew. But I did really relate to him when he was talking about being in the shadow. And I think that's just a common younger sibling thing, but again, as a child, you don't see it that way. You're just trying to find or make sense of it.

Ashley: Yes.

Iva: For me, I made it a cleft thing. Like, oh, he's this Mr. Everything where I couldn't do sports. And so you might've felt the same.

Ashley: And it comes back to the story that you tell yourself, right? Because I was the older one, and so I had a cleft, but I was overachieving and overperforming or whatever. So it's more of like,

Iva: You were telling yourself a story and then he started to tell a story based off the story that you were telling

Ashley: And you were telling a story based on being the younger sibling and all of that. It's just fascinating.

Iva: It's really great that we had this conversation, our hope that other people can begin to have these conversations with their siblings.

Ashley: Yes, and I think something that I learned from this too was just how important it is to have those conversations. If I had known that he felt excluded or something like that, we could have done something about it.

Iva: Yeah, I think so. And I think they both kind of touched on this onto the parents of just trying and the best that they can to make it feel like a full team, and that someone's not sitting on the bench.

Ashley: Right. As long as the person who was born with the cleft is okay with it, almost talking about it more than less because in so many ways, and this might be hard for people to understand who aren't in cleft families, it is just part of life at some point, it just becomes part of life, the surgeries become part of life and for the person going through it, but then also the family and the scars are just part of the person. And so yeah, actually being explicit and having those conversations.

Iva: Exactly.

Ashley: It's really important.

Iva: It absolutely is. This might be my favorite episode. This might be my favorite episode. Don't tell the Moms.

Ashley: It was so good. Well, now they can't listen to this episode, or we'll have to have 'em end it early.

Iva: That's fine. I still stand on it. I think I still stand on it. It's fine.

Ashley: It was really special. Yeah, I definitely think it has given unique perspectives. I think that's our show for today. Don't forget, as always, we would love to hear from you and what your experience was like navigating cleft and your

siblings. Please let us know. We always like to hear from you. You can find me on Instagram @cleftloveig or on TikTok @CleftLove

Iva: And you can find me on Instagram and TikTok, @realsophisticatedjoy. Don't forget to go to [smiletrain.org](https://smiletrain.org) to learn more about all of the wonderful things Smile Train is doing for the cleft community around the world. You can find us on your favorite podcast streaming site. While you're there, don't forget to leave us a five-star review. Thank you so much for listening, guys.

Ashley: Bye!

Iva: Bye!

Announcer: If you like the show, be sure to subscribe, leave a review, follow us on social, and tell all of your friends to listen. Questions or episode ideas? Email 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 Ballou and Ashley Barbour. 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 Smile Train has developed a sustainable model that empowers local healthcare workers around the world to provide life-saving cleft treatment to all who need it in more than 70 countries. 100 percent free. Learn more at [SmileTrain.org](https://SmileTrain.org).