

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Iva Ballou: Hey, everyone. Welcome to the Love Meets Joy podcast on the Smile Train podcast network. We're super excited about today's episode. We always say this, but today it is one million. Like I cannot believe we've

Ashley Barbour: So exciting!

Iva: Right? Ashley's so excited. But before we get into that, I'm Iva Ballou. I was born with a bilateral cleft lip and palate, I'm the CEO of RealSophisticatedJoy and a cleft confidence coach.

Ashley: And I'm Ashley Barbour. I was born with a bilateral cleft lip and palate as well. And I'm the creator of CleftLove. And by day I work as a teacher consultant with students who have hearing loss.

Iva: So we've been talking about doing this episode for a while. I cannot believe it's here.

Ashley: I'm so excited. I cannot wait.

Iva: Do you think the audience knows what's going on?

Ashley: Probably not, but we've been teasing it for a while.

Iva: We have, we have so audience, as Ashley just mentioned, we've teased for a while that we had to have a conversation with two very important people in our lives. And we're going to kickstart that off with today's guest. A very, very, very important person in my life. The woman who taught me that I have a cleft and that a cleft does not define me, the woman who, although I did not have any cleft representation growing up, I could always look to her with her lipstick, her style, her dress, how she handled things. And I could remember saying, I want to be like that when I'm growing up. Aw. And so if you haven't guessed by now, today's special guest is my mother. Carolyn Ballou welcome. Carolyn Ballou or welcome mom.

Carolyn Ballou:<laugh> just, thank you.

Iva: <laugh> all right. So we're going to talk to the audience. Feel free to say whatever you can spill the beans about me, although I don't know what she's going to say. So who knows audience?

Ashley: I'm so excited to talk to you later, Miss Ballou. <laugh>

Carolyn: Nice meeting you as well, Ashley

Iva: Get, get the tissues ready.

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Ashley: So

Iva: Did you know that I was going to be born with a cleft?

Carolyn: I think maybe in the third month or fourth month I got this excruciating pain. And after a while I went to the doctor okay. To my gynecologist. Mm-hmm <affirmative> and he, uh, referred me to another doctor and I said, okay.

Iva: So do you think that he knew the first doctor that you went to? Do you think that he knew

Carolyn: It wasn't until later on, he referred us to, uh, this other doctor mm-hmm <affirmative> and in the room when he was doing the sonogram and everything, uh, he just said, mm. So we didn't think anything about it. And then he called us for a meeting in his office

Iva: The same day,

Carolyn: The same day. Okay. Yeah.

Iva: Mm-hmm <affirmative> okay. And so, so he took, he takes you and dad back there. And how does he present it to you? Does he cut around the bush or does he,

Carolyn: Well, no, he had me, you know, we, I got dressed and I went to his office. Um, my husband and I went to the office and he, um, just started talking and I, I think he was just as uncomfortable talking to us about it as we were to, Hey, what, what is it? And he told us that, um, that our baby had a cleft, whatever that was, and we were clueless and he asked us, what did we want to do? And I, I couldn't understand, well, what is he talking about? What we want to do, you know, it's our baby. We have a baby, a baby girl at that. So he said, okay. And we left out feeling just as happy as we came in there. Like really wasn't a big deal.

Iva: Really? You, you never told me that, like you walked out, like nothing.

Carolyn: I meant we having a baby and she may have a cleft had no clue what that was.

Iva: So for the audience, I've disclosed before that my father has passed away. But what did dad say? Did he say anything? No, he was good for a good saying or something.

Carolyn: No, I can't recall him saying anything, but we just went, had dinner and there it is.

Iva: But at that time you had, no,

Carolyn: We had no idea what a cleft was. Okay.

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Iva: Some

Carolyn: About that. Yes. I can remember. Um, the doctor that we had that delivered you mm-hmm <affirmative> um, <laugh> he had another doctor help him who also had a cleft. Oh, really? Yeah. So I thought that was really nice because he, you know, he was trying to explain that to me. Mm-hmm <affirmative> while I was in labor and I could care less about what he had <laugh> <laugh>, you know, let's get on with the show. Okay.

Iva: Did you make sure to put on lipstick?

Carolyn: They don't let you put lipstick on when you're having the baby, but

Iva: After

Carolyn: Oh yes. <laugh>

Iva: Yes. That's the must. Okay. So I was born with a bilateral cleft lip and palate. Right? So that means that I did not have my outer lip nor did I, was I able to section

Carolyn: You had the, the lip, but it was split. It was split. It was split.

Iva: So what was

Carolyn: Feeding,

Iva: Like did you breastfeed me or,

Carolyn: Well, fortunately for us, uh, when I look back over it, Nemore's had a cleft coordinator who was there and uh she came in immediately and tried to help me feed you. And it, it, it made it easier. So I did the best I could with what I had.

Iva: And, and so what did you have, like what did I, do

Carolyn: You remember? There was a certain bottle. Okay. A certain bottle and I was trying to breastfeed you, but you couldn't latch on, so it was trial and error, trial and error.

Iva: Okay. And so speaking of trial and error as I'm, I'm being born and you're going through this new, I guess, new, normal of having this cleft baby, you also had my older brother.

Carolyn: Right? Do you? He was

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Iva: Five. He was five mm-hmm <affirmative>. Do you think that that was also a challenging aspect of me having the cleft of trying to navigate, caring for me and caring for this other baby?

Carolyn: Not really because Isaac always wanted the baby. He always wanted the baby <laugh> he always wanted a baby. I guess he knew. Or he felt that you know, it shouldn't be just one. It should be him and somebody else, another child. So he was so thrilled. Um, I recall one day, um, you were only maybe a couple of weeks and I was in the kitchen and he came in the kitchen holding you. And he said, uh, come on baby sister, mommy don't know what to do with the baby <laugh> and I said, you're right, mommy don't but let me have and put it back. So she'll be safe. So he was real. Okay, everybody.

Iva: So he was happy in that aspect, but you know, some of the conversations that we've had in adulthood is that he sometimes felt left out of my cleft experience.

Carolyn: And he probably was because I didn't know, the days of the week per se, my whole focus was, um, making sure you got to the, uh, doctor's appointments. Yeah. When and where, in fact, I tried to keep a journal whenever I could find time. And one of the things I said the day after in my journal,

Iva: Oh gosh,

Carolyn: Okay. I said, Iva, you look so pretty to me today. Everybody's being so nice. But they're doctors, doctors everywhere. I'll do whatever it takes to fix your face and your lip together, trusted in God. Everything will be right. I'm

Iva: Couldn't even get it in, but it's okay. And I think that's why I always say I'm very thankful for having you as a mom, because one thing that you really instilled in me was like advocating you really instilled advocacy in all of my being, where did that come from?

Carolyn: I really don't think I instilled that in you either. Because when you were born, number one, you were born breach. You had your umbilical cord wrapped around your neck several times. So <laugh> thankfully it was a c-section. So you came here fighting and I just, and my husband need to just make sure you understand that you're in a different mm-hmm <affirmative> you're no different from anybody else. Mm-hmm <affirmative> and I've always said that everybody's got something. Yeah. They just can see yours.

Iva: Yeah. You, you would always tell me that you would always tell me everybody has something. Yours is just more visible. Yeah.

Carolyn: Mm-hmm

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Iva: <affirmative>. Now I do think that we have to talk about the fact that not only was I cleft affected but I was a black woman. Mm-hmm <affirmative> do you think that was a little different to navigate as well? Because you know, in our community, it's not always prevalent, especially back in the eighties.

Carolyn: Well, I think kind of either we put blinders on. Yeah. Because no matter what everybody else was doing in the world, our primary focus was you. Right. So it didn't matter to me. Like I said earlier that I was going to do whatever I had to do. Mm-hmm <affirmative> to make sure that you were okay.

Iva: Even slapping me down in the grocery store,

Carolyn: Even knocking you down in the grocery store.

Iva: So we have to tell this story. When I think about my mother doing this, it's not who she is. So they really got to you that day. What happened?

Carolyn: Well, she was born in September and Thanksgiving was coming up. So I went to a store, well known store that sells turkeys and hams. And, um, I had, I had you all bundled up because I didn't want number one, the cold weather and number two, I didn't want people just looking at her. You know how people see someone with a new baby, they want to see it. And, and they did. And um, people were making comments like, oh, were you on drugs? Oh, you got a hare lip that wasn't the day to say that to me because something happened to me. <laugh> and I started unraveling her out of the blanket, taking her hat off her head. Then I held her up. This is my child. This is my child. There's nothing wrong with her. And then at the same time, something struck me and I looked around and you should have seen the look <laugh> on the people's faces. So I had to go around, snatch the turkey and then pick up all your stuff and wrap you back up so I can get back to the car.

Iva: <laugh>

Carolyn: And I think that's the day that I realized that this is my child and she's going to be okay, she's going to be fine.

Iva: And that's how we were doing it. And we were.

Carolyn: Yeah.

Iva: And so you said that you were going to do anything to, you know, help me out and get me to where you felt that I wanted to be. And so part of that would go into my surgeries. You know, I had quite a few. Did you ever have like any like hidden fears or anything like that? Cause I have to tell you, I was actually more afraid of the surgeries than I let on.

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Carolyn: Well, you, you made it kind of easy. Uh, the first couple times, when any mother, you know, they, your child is taken from you for surgery. I don't care if it's something minor, you, you lose control. You have no control over that. So I was, um, really nervous and prayerful the crying and we would always have an entourage of, um, people around mm-hmm <affirmative> in fact, one story I wrote in here about we were getting ready to have surgery and um, I wrote, oh, Iva, you are so confident and sure of yourself today, you're going to have surgery. And when we got out the elevator, our pastor was there waiting for us. And you are so happy. We were also joined by your Daisy leader, as well as friends from work. You are so brave in the light of the entire floor. Everyone is amazed at your bravery. I'm crying because I'm scared for you. I don't want you going through the pain and I only want the best for you as they take you away. Either you are still brave and wave goodbye. I realized just how special you are. No matter where you go, you make friends. I talked with another parent while I was waiting the five hours when you're in surgery. When you came out, you didn't complain. You don't ask for pain medication. You asked for a baby doll.

Iva: So you talked about the fact that you sat there for five hours. You never would leave the waiting room.

Carolyn: No.

Iva: So what was going through your head during that

Carolyn: Time? Well, I would talk to other people who seemed to be a little more fearful than me. Okay. Uh, that it was going to be alright. Trying to encourage them and I trust God to do what it needs to do. Okay. And I didn't want to have fear and put that fear on you. Right. And your daddy was there. So we just did our best. We could several times, um, when surgery was, uh, needed, be it for your cleft palate or be it for your eye, uh, be it for your dentistry. The insurance company would say that it's not medically necessary. And then I would have to write letters, get the doctors involved, and write to these insurance companies to say, yes, it is mm-hmm <affirmative>. This is something she was born with from birth. It is medically necessary. And so I got to learn a lot of terminology <laugh> and a lot of words. And, uh, fortunately, fortunately, and blessedly they always eventually came through, but it is a hurdle. So during that process, I began to help some other people that came to the cleft clinics that we can do this. We just have to stay vigilant and we just have to stay focused. Mm-hmm <affirmative> cause we are your promoter. We are your ally. We are the person who's standing up for

Iva: You. And see, that's why I always felt like you were big on advocacy because you didn't know what you were doing. You just knew that you had to do it.

Carolyn: I just knew I had to do something because my child is entitled to this. This, this happened to her. So you all, I have insurance, I pay my bills. So there you go.

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

- Iva: <laugh> that's it. There you go. That's it. Okay. <laugh> mm-hmm <affirmative> and so what would you say is, or was my, my least successful surgery? And it could be from your point of view or from my point of view,
- Carolyn: I think the least successful one was when they were doing your nose mm-hmm <affirmative> and after that, doing the nose surgery, you started snoring <laugh>. I mean, I could hear you in the garage, what? And I knew something wasn't right. Something wasn't right. I never knew this. So I went back, I took you back and they had to correct that.
- Iva: I never knew that. Yeah. <laugh> you held that one in <laugh>. Okay. And what was my most successful surgery?
- Carolyn: I think the most successful surgery was your very first surgery. Okay. Because that let me know. Okay. We can work with this. There are some things we can do. And when they did the first surgery, they laid out an outline of what's possible going to come mm-hmm <affirmative> next. So I think the very first surgery was the most successful because not only did it help you, it helped us, uh, to understand we can do this. It can be done.
- Iva: And so just really quickly. Can you think about any like contraptions that I had that you thought I can't put my child?
- Carolyn: Uh, there was a, there was a, uh, a cap and you fasten it up. Mm-hmm <affirmative>
- Iva: The orthodontic
- Carolyn: One, right? The orthodontic one. So that was one. And then you had another one with the braces? I had the full one. Yeah. I didn't know I had that. Yeah. You had that for a period of time.
- Iva: I didn't know that. Yeah. Oh, right. Well, I think we could talk about this forever. You have definitely let me know some things that I didn't even know. I hope that the audience is enjoying this so far. And after the break we're going to hear from Ashley. She's going to have some questions for you. You ready for that?
- Carolyn: Yes.
- Iva: All right. Let's see what we got.
- Speaker 4: 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

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

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. Visit 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.

Carolyn: Whenever they need it.

Ashley: Hey, everyone. Welcome back from break. And I'm super excited to now be joining Iva and Mrs. Ballou. This is our first-time meeting and I have to be honest with you. I was like kind of nervous coming into today because I was like, I hope Iva's mom likes me. <laugh> because I've heard so much about you and just the positive impact that you've had on Iva's life. And so I just feel really honored to have the chance to meet you and talk with you today.

Carolyn: I'm excited as well. I, I, I hear I was talking about you all the time and the things that you are doing. So I finally get to meet you.

Ashley: I know it's so fun. Um, so it was very interesting to me as I was listening to you and Iva talk at, you know, in the first segment, because I noticed that there were similarities between her journey and my journey. Um, even things that I didn't even think about when you were talking about contraptions, you were talking about her having like a cap, um, was that like a hat? And then it went under her nose.

Carolyn: Yes, that's exactly. I had

Ashley: That too. And

Carolyn: I still have it somewhere.

Ashley: Uh, yeah. And it's so funny because my parents always thought that it was something my surgeon created and they were like, we don't know how this was beneficial or if it did anything and

Carolyn: You know, it's real. <laugh> <laugh> I obviously black that out. Okay. That's right. You're too young. Great member. Okay. Okay.

Ashley: Yeah. Cuz it was before any surgeries. That's what mine was. That's so funny. I'll have to send Iva a picture of me and mine and see if it looks anything like hers. Did I bet it did

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

- Carolyn: We have to do that? I think I still have the hat.
- Ashley: Oh, that would be so cool. I, um, I wonder if my parents have mine, it might be in the attic somewhere. I'll have to,
- Carolyn: I have to find it <laugh> yeah.
- Ashley: Um, so something that Iva and I have talked a lot about is a lot of the challenges around growing up with cleft and the surgeries and, and all of that. I was curious though, from your perspective, what has been the most challenging part of it for you as a mom?
- Carolyn: I guess the most challenging part has been when people, uh, stare or when little kids. Um, yeah, in fact I had to, well, my husband had to help me not say something mean back to them. Yes. Yes. Because I meant this is my child and um, it's, it's hard to see people doing that to your child. That's a form of bullying even then. Yeah. And nobody said anything and then, you know, to me, everything else I could deal with, but there would be several times I would be like,
- Iva: Mom, it's okay. It's okay. And she's like, mm-hmm Nope, no, no. And it's like, yeah, we don't understand. She didn't care. Sometimes
- Ashley: I think it's harder for our loved ones to see us endure that because for us, it's sort of something we see regularly, right? Yeah. Like it's very little, sometimes it's very subtle and yeah. But we're used to it. And then when someone does something that's less subtle, then you know, it it's sort of, and
- Iva: She would always catch it.
- Carolyn: Yeah, I would.
- Ashley: Yeah. I bet that is a really challenging part of it. Something else I thought was really interesting is you said that you were never, like, you didn't have any fears before Iva was born related to the cleft. And I was wondering with her brother, because he was older. When did you tell him that she was going to be born with a cleft and how did he react? The first time he saw her?
- Carolyn: Like I said earlier, um, he never asked that he just loved her.
- Iva: He really never
- Carolyn: Asked. He never asked that he never asked her, he wanted the baby <laugh> he wanted the baby sister. Aw. And he never asked that he was, uh, more protective of her. Yeah. And you know, there was a five-year difference in them. Mm. So

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

he, he just never asked, but I did explain it to him. And when he first saw her, it was like, there's nothing wrong with her. She's so pretty. Come on. The big brother I met.

Ashley: Oh

Carolyn: <laugh> it was the sweetest thing. Yes.

Ashley: That's really special. Cuz I think that that's something a lot of parents struggle with now when I see, you know, in Facebook groups or something, they're always worried about how to tell the older siblings and how to prepare them and everything. But I think it's such an important message that you have that the siblings just love them. Exactly how we are, you know? And I think that's something that's so special about our families too, is that they almost don't see it.

Carolyn: That's right. They don't see it.

Ashley: Yeah. Did you, after Iva was born or when she was growing up or something, was there something that happened like a positive experience that really made you feel like, okay, everything's going to be right.

Carolyn: Well, several of them, um, Iva met, she made friends easily, even in kindergarten. I mean she just met friends and then our church had a big, huge celebration and I never not let Iva do anything. She participated in Sunday school. She participated in the Easter speech. But this time Iva gave a speech in front of over a, a thousand people at the church. Oh

Ashley: Wow.

Carolyn: Then I thought, my goodness, how is this going to go? I do remember that. But she did it. And I said, okay, she got it. Wow. She'll be okay. Yeah. She'll be okay.

Iva: Remember we talked about the stories that we tell it's like, I wish I would've kept that little girl.

Carolyn: Yep. She, she did well and I figured okay, if she, she can do this, she can do anything.

Ashley: And how old did you say she was when she did that?

Carolyn: She couldn't have been no more than six or seven.

Ashley: Wow. That's amazing. A thousand people. You were famous back then, Iva!

Iva: <laugh> I guess so I guess so <laugh>

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Carolyn: I, I always tried to put her in situations where she's no different. You're no different. Yeah. You're no different right. Than anybody. Yeah. And just to feel confident.

Ashley: Yeah.

Iva: Thankfully growing up, my brother had his group of friends and then my group of friends, but they were all in the same age. We would all play together and you would go to their houses. And my mother was, and dad were quick to let the parents know, do not give her special treatment. Do not coddle her.

Ashley: Yeah. She

Iva: Can

Carolyn: Do it. In fact, most of the parents always wanted their children to come to be around Iva because of the amount of, um, confidence she had so, oh,

Ashley: I love

Carolyn: That. They wanted to be with Iva. They wanted their children to be with Iva. She's so confident. She's so sure

Iva: That is true. It would be like, if I was going, you can go.

Ashley: I love that. And do you think that there was any point in her growing up that that confidence wavered?

Carolyn: I don't think it wavered. I think it probably changed a little, uh, especially when she was going into new school settings. Yeah. Because the people were not used to her and then she always overcame that she always drew them in to her, you know, naturally you're going to have some

Ashley: Of course,

Carolyn: But I think she was pretty much, well I, everybody knew. Um, but I would shut her because the way the school system was set up, she would have to walk down this hall and kids would be on both sides. Mm. So were they going to make fun of my child?

Ashley: Yeah.

Carolyn: You know? Yeah. I worried about that. I didn't want her to have to experience that, but that's life. It's life.

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Ashley: Yeah. That's true. Like you said earlier, we all have our stuff and everybody has to figure out how to deal with whatever their stuff is. Right. So that's really interesting. And thinking about all of the surgeries that Iva's had, because I know she's had a lot. Is there one that you found particularly challenging to watch her go through as a parent or one that was emotionally taxing for you as a parent?

Carolyn: I think the one that was most challenging for me, like I said earlier, was that first one, you know, when your child leaves you to go back in that room and you can't, you can't go with her. Oh was I? You can't fix it. Yeah. You were just a couple of months. Yeah. You can't fix it

Ashley: And she's so tiny. Yeah.

Carolyn: And she's so tiny. Yeah. And who's going to protect and who's going to do this and oh gosh.

Ashley: Yeah. Probably the first time you have to hand her over to a surgeon and just put all of your trust in them.

Carolyn: And that was very, very hard. Even though I knew the surgeon still doesn't matter. Doesn't make it any easier the first time. No. And then you kind of right. Build up your trust, your faith.

Ashley: Yes. Yeah. Cuz every time it happens and she comes out okay. And better and, and all of that on the other side then, um, I'm sure that that helped a lot. And at what point did you decide to let Iva sort of take control of her own cleft care? Because I know for a lot of us, there are a lot of sort of optional surgeries that we can have that are more cosmetic. And at what age did you start letting her take the reins?

Carolyn: I think when I either got to, um, maybe middle school. Yeah. Middle school. Yeah. She would say she want this. She want that. And we still, she probably still wants some more stuff done. So whenever she would say she wants, um, I would try my best to make it happen. Yeah. That is with the cooperation of the, uh, surgeons and you know, the dentist and she had them in the palm of her hand.

Ashley: <laugh> it always sounds like Iva was a better patient than I was so

Carolyn: <laugh> she really was a good patient. She took the, uh, she used to call it her boyfriend where the intravenous line. And she had dragged her through the hospital. That's a boyfriend and oh

Iva: Gosh, she, she

Carolyn: Was a good patient.

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

- Iva: So yes, guys I've always had a boyfriend. It was the, the IV <laugh>
- Ashley: You didn't talk about him during our dating episode. I know
- Iva: I was trying to keep him on the
- Ashley: Mom just spilled. It all
- Iva: Was spill today. We, we did say that <laugh> but we sure would, but I think that's how she got me to be comfortable with it because it, it went with you everywhere. It's supposed to go with you everywhere. So she was like, yeah, it's your boyfriend. I'm like, okay, come on,
- Ashley: Love it. So I also have to tell you, Miss Ballou I wore my lipstick today, especially for you. I don't know if you can see it
- Iva: <laugh>
- Ashley: I was like, I need to impress Miss Ballou because I know how much she likes it
- Carolyn: Even. And they, when I had both my children don't bring my baby to me without my lipstick on. Because I wanted to look a special way for them.
- Ashley: I love it. That's why I knew today was a special day. So I had to make sure I wore it.
- Carolyn: Good job. Good job.
- Ashley: Um, so I'm curious when Iva was growing up, did you talk to her about her cleft a lot? And do you remember like the first time she noticed it and what you did?
- Carolyn: Um, no, I didn't talk to her a lot about it because I didn't want that to define her. Yeah. I didn't want her that to define her. That makes sense. You right. Are you're either and I either didn't need any more encouragement. She really didn't.
- Iva: <laugh> <laugh> the stories we tell. Because I totally told myself a totally different story I told myself what totally
- Carolyn: Different. No she didn't. Um, so you know, if she asked me any questions, I would answer them or try to, and we went monthly to this cleft palate clinic. So a lot of questions were, and then I will be flirting around there talking to every and anybody, you know, trying to encourage them. She was a good promoter for the other children <laugh> and I sometimes I would wonder is she doing that for me? Or does she have some deep inner feelings about what's going on with her? What she has to endure? I often wonder and prayed about that.

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

Iva: I think it was both.

Ashley: So like if her social butterfly ness was sort of a reaction to the cleft,

Carolyn: Right? Yeah.

Iva: Mm-hmm <affirmative> and I would say it was a little bit

Ashley: Of both. Yes. I have often felt that way about myself or what I've realized as an adult looking back on it. It was kind of a way to like camouflage mm-hmm <affirmative> the cleft because then if you could be this like shining star, this shining example, then people wouldn't notice. Yeah. The other stuff.

Carolyn: And also, uh, I made a point to, uh, dress her. So that would be one less thing that people have to say or look at.

Iva: So the reason why I dress the way I dress now is because of her, like she would have me in the dressiest of dresses and it never made sense to me because she would always get upset because they would like, yeah, like \$10 hair bows on a, on a child, on a little kid. Yeah. And she would be like, well, they took all your hair bows. I'm like, well, what did you think was going to happen? <laugh>

Ashley: She had to make you look good Iva.

Iva: She was really good about that. And then my dad would be the balancing act because like the, you know, like the big foofy church dresses, she would add an extra. So it would be really my dad because he would be like, he would take off the extra and be like run free child, run free. Thank you.

Ashley: How you could move around a little bit more. So it's interesting to me because I feel like the picture Iva has painted of herself as a child is she thought that she was shy for a period of time. Do you think that she was ever shy?

Carolyn: No. No, I don't. I don't. I don't. People do not believe. I don't. Um, even the first time I took her to school the very first time I took her to school.

Iva: So I didn't like have my head down.

Carolyn: No, you didn't.

Iva: You didn't. Okay. Maybe not.

Carolyn: She wasn't shy because um, we had gone to, um, to a restaurant or something. Yeah. And the waitress said something to Iva and I heard just what she said. She

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

must have been five. Now, who would approach an adult with that kind of tone or language?

Ashley: Iva did apparently <laugh>

Carolyn: Iva did. Yes. And no matter where we went, everybody knew Iva, no matter where we went or whatever setting we were in. And to this day, they still ask about Iva. Sometimes they don't even ask about my son who's the oldest. They want to know how Iva is doing

Iva: <laugh> okay. So that was when I was like five. But what about you don't think that there was a shift when I was in high school?

Carolyn: No, because you thought you were all that and a bag of chips because you were driving that car.

Iva: Oh, because I had a car mm-hmm <affirmative> that was different. Yeah. Cause I had a car, but I'm, <laugh> not on a social setting, you know, I didn't really date.

Carolyn: No, you and that's, that's an area that, uh, concerns me about, would she be, be invited to the prom? Would she go to dances and um, she did. And so I was so excited that she did get invited, that I, um, rolled out the red carpet. I got some red carpet and rolled it out. So when she came in, everybody would Iva.

Ashley: I love that. Mm-hmm <affirmative> oh my gosh. So, um, so do you think that there's anything that you did that helped her build that confidence that has led her to who she is now? Or do you think it was just always within her?

Carolyn: I think it was always there, but I think her father and I just really focus on Iva being who she is, either understanding who she is and she doesn't have to be anything. Other than that, don't treat her any differently. You can do what everybody else does either. Let's go with it.

Iva: But you don't think that I learned from you?

Carolyn: I don't know about that. <laugh>

Iva: Yes. I think that I am you. I think that I watched you, you know, as I've said before on the podcast that I didn't have someone who had a cleft that looked like me, but I always tell the story about how you were such a fierce. You were just like, you were fierce in your job. You were very fierce in being a mom. And yes, even though, you know, she worked a very high demanding job during the week, on Saturday, you were my troop leader,

Carolyn: Right. With lipstick,

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

- Iva: With lipstick, doing it all with lipstick. <laugh>
- Ashley: Always, you know, I think what has been really interesting about talking today is seeing the sort of two experiences. So like your perspective, Miss Ballou might not have been the same as what Iva feeling maybe at the time. And so, and that's just been a really interesting thing for me. Mm-hmm <affirmative> and as much as I want to talk forever and ever, and I think now we have to move on to our Smile and Slay segment where we talk about questions that we've heard from our friends and family.
- Iva: Okay, perfect. And so Mom, as Ashley said, this is one of our favorite sections, the Smile and Slay. And this week's question is what you would say to a new mom who's just finding out about a cleft diagnosis of their baby.
- Carolyn: I guess the first thing I would tell them is that it's going to be okay. And that you as a mother will have to be the advocate for your child. You will have to make sure that they get all that they need and deserve. Yeah. Uh, be it, the doctors be it, the health care insurance, whatever it is, your child is dependent on you to help them go through life. And also like I told Iva, you have a cleft, the cleft doesn't have your child.
- Ashley: Yeah. So true. So thank you so much, Miss Ballou for being here today. This was truly an absolute honor for me to finally get the chance to meet you. And that's our show for today. Thank you all so much for listening. We'd love to hear from you as always. You can find me on Instagram at Cleft Love IG or on TikTok at Cleft Love.
- Iva: And also Mom, I want to say again, thank you so much for being on the podcast. Thank you for being my mother. I could not have been where I am today without you. And you can find me on Instagram and TikTok at Real Sophisticated Joy and for a special treat, Carolyn, you'll be closing us out.
- Carolyn: Okay. Uh, don't forget to go to smiletrain.org, to learn all about the wonderful things that Smile Train is doing for the cleft community around the world. And also you can find us on your favorite podcast streaming site. While you are there don't forget to leave us a five-star review and real sophisticated joy to everybody.
- Speaker 4: 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. We can't wait to hear from you. Love Meets Joy is a product of Smile Train. Our hosts are Iva Ballou 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,

Love Meets Joy Podcast
Episode 6: A Parent's Cleft Journey: Meet Carolyn Ballou
Transcript

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 [smile train.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.