

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Ashley Barbour: Hello. Hello. Hello and welcome back to the Love Meets Joy podcast on the Smile Train podcast network as always. We're incredibly excited for our episode today. My name's Ashley Barbour. I was born with a bilateral cleft lip and palate. I'm the creator of CleftLove. And by day I work as a teacher consultant with students who have hearing loss

Iva Ballou: And I'm Iva Ballou. I also was born with a bilateral cleft lip and palate, I'm the CEO of RealSophisticatedJoy and a cleft confidence coach, Ashley, tell the audience what we're talking about today. I can't wait

Ashley: <laugh> I can't wait either. It's an episode that I feel like I've been waiting for for so long, because I'm really excited to finally get to introduce everyone to my mom. Nice. Yeah. It's <laugh>, it's always so interesting because for both you and me, we write a lot about our personal experience going through this cleft journey. Right. Right. And sometimes I think, especially when you're the one who grows up with a cleft, you kind of forget that there's this other side, this other journey that's going alongside you at the same time. Yeah. And so I'm really excited to get to talk to my mom in the first half and kind of delve into what her experience was like. And then to bring you back after the break so that you have a chance to meet her, because today will be the first time that you guys are meeting as well.

Iva: I know. And I'm so excited that she's allowing me to ask some questions and I know that the audience is going to enjoy it as equally as we are enjoying it. So let's get into it.

Ashley: All right. You ready? You ready? <laugh> ready as you'll ever be. <laugh> all right. So something that I think is different about our story, that's sort of different compared to a lot of people's today is I was born in 1985. For those of you who don't know, and back then they didn't do ultrasounds, at least at our, at your hospital, they didn't do ultrasounds unless,

Janet Barbour: Well, they just didn't do them because everything was fine. Yeah. Um, whether they did them more often for other people, I'm not sure,

Ashley: But, but for us, because

Janet: For us it wasn't done. It was there was no need. There was no

Ashley: Cause there wasn't anything alarming. They didn't see anything alarming.

Janet: Right. It was a so-called normal pregnancy.

Ashley: Yeah. And then, so when was it that you did find out? So a lot of people nowadays find out while they're pregnant, but for you, you didn't, what was that story like?

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Janet: So let me think it was on the delivery table.

Ashley: Yeah. We, there

Janet: Were, there were a lot of complications to begin with. You were, uh, in distress, there was actually, after you were born, there's meconium staining. So there's a lot of chaos going on yeah. In the delivery room at the time. Yeah. Um, you know, during the delivery, couple of things happened and I'm not sure what, what the shock was, what I recall and who knows that, what the truth is that your head popped out and then it went back in again,

Ashley: While you were,

Janet: And I going, oh my God.

Ashley: Yeah. <laugh> I just pushed that out. And now my

Janet: A Resident or somebody at the other end said, oh my God, I've never seen anything like this before. So when at the time I thought it was referring to

Ashley: The head coming out and going back in. Yeah.

Janet: Yeah. Um, now I don't know if it was the cleft or whatever, but anyways, so then they, they kind of presented you and then whisk you away because of the meconium staining and distress and all

Ashley: Of that. And it sounds like because there were all those complications, it was hard to, um, there, there were a lot of people in the room.

Janet: There were a lot of people in the, even the pediatrician was in the room and I'm not quite sure why he was in the room, but he

Ashley: Was. Yeah. Yeah. And you, you had never seen a cleft before. You didn't know anything

Janet: About not an unrepaired

Ashley: Cleft. Right. Did any of the staff who were in there talk to you?

Janet: The, the one person I remember is the anesthesiologist had a very calming voice. Yeah. Put warm towels on me because I was shaking. You know, that happens after delivery. Yeah. And he was, he was just so kind, but then I thought about your dad <laugh> yeah. And he was in the corner. Yeah. And I felt like

Ashley: <laugh> yeah,

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Janet: This shouldn't be happening. I shouldn't be crying.

Ashley: <laugh> it's OK.

Janet: Um, but he was off in the corner I'm in my mind, of course. I didn't say anything, but it was like, well, who's there for him. Yeah. And it

Ashley: Felt like you were separated.

Janet: Yeah. Yeah. And that was, it would've been much better if we'd been together, but they, they all kind of took their tasks and did

Ashley: Whatever. And then what was it like feeding me. So I was basically born without a palate. Right. And so I wasn't able to breastfeed for sure. And then they probably quickly realized I wasn't going to be able to just use a regular bottle either.

Janet: So I'm not quite sure how, what the timeframe was, all of this, but a nurse found a small four ounce glass bottle. Yeah. And a lambs nipple, but not a typical lambs nipple because they're pretty hard. Oh. And it was, it was extremely soft and long.

Ashley: Yeah. So you were

Janet: Able to just kind of press down and kind of get milk out that way

Ashley: To express it. And it was long. So it just went to my throat. Yes. So it didn't come out my nose as much.

Janet: Right. I don't remember it ever coming out your nose. So that's, it might have, but I don't recall

Ashley: That. And so you, you had the one bottle and the one nipple. And did you ever get any additional nipples?

Janet: We absolutely tried everything. Um, the, the nurse from the pediatrician's office went to farms and went to and brought in traditional lambs nipples and called all kinds of places. And we got some commercial cleft palate bottles that

Ashley: Didn't

Janet: Work. Yeah. But it didn't work. Nothing else worked. So we were stuck with this one nipple in this one little glass bottle

Ashley: For every single feeding

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Janet: For every single feeding until they made a plate for your, and I think there's a name for that. A plate

Ashley: Curator, I think. Yeah. I think is what that's,

Janet: But for your palate and then you were able to, to get a little more suction and

Ashley: More regular bottle,

Janet: Uh, a commercial bottle.

Ashley: Gotcha. Like a commercial

Janet: Cleft. Yes. Not a feed bottle, a typical baby bottle.

Ashley: That's so interesting. Before I had any of my surgeries or treatments or anything, what was it like when you sort of had to take me out to the grocery store, to the mall or, or whatever? Before I was,

Janet: Well, I didn't for

Ashley: Treated,

Janet: I was going to say a long time, but probably a couple of weeks. Yeah. Several weeks. And then it get to where you got to go. Yeah. You just have to get out of the house. And in the beginning, I, I was pretty protective and yeah. And hold you close. And then it got to where it's like, uh, oh, well <laugh> yeah. Too bad for you. People <laugh> if you don't like it, this is my beautiful baby. And if you don't like it then too bad, it was a good feeling actually to, to accept you and to feel not,

Ashley: I know you accept you, but

Janet: Yes. Um, to, to just not care what other people thought.

Ashley: Yeah. And that probably has helped you throughout all of this. Probably because

Janet: Perhaps yeah.

Ashley: Yeah. So it sounds like sometimes when you would take me out, it was kind of overwhelming. Because people would look or stare or say something like what did someone say once? Did you know that they can fix that?

Janet: Yeah. Somebody actually said, you know, they can repair that. <laugh> thanks. I didn't know that. But you know, things aren't meant it's they're not cruel. They're

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Ashley: Intentionally.

Janet: Yeah. It's not intentional.

Ashley: Right. Which is why more education is needed. Um, were there any people in the beginning that sort of gave you hope that things were going to be okay or that, that it wasn't going to be overwhelming all the time? Like did anyone say anything really kind or, or they didn't notice?

Janet: Oh absolutely. There were many, many kind people. So I don't want it to sound like everybody.

Ashley: Right.

Janet: Right. Was, was saying these negative comments, but there was a babysitter once that had not met you, we were over at your aunt and uncle's house and we were going to go out and the babysitter came and the first response she had was, oh, what beautiful eyes she has. Yeah. And it was like, thank you for, for noticing the beauty. We were in the hospital for four days. Oh wow. The office had this woman came up and she had an eight year old son who had a cleft lip and palate. And you know, she said something that I thought was helpful, but other people may not. But it was that at some point you're going to be thankful that this is the disability your child has. Yeah. And not something else because there's so many other things in the world. Yeah. And it was hard to appreciate at the time. And it's, it sounds a little kind of not PC today.

Ashley: Yeah. But, but it's helped

Janet: You. It's true.

Ashley: Yeah. Right. That helped you on that journey. Was there anything that you and dad talked about after I was born that you, you know how you were going to navigate this together cause you were in it together. And was there anything that you felt like you had to do or not do in order to accompany me on this journey?

Janet: One thing that we felt was that we could not feel your pain for you. Yeah. That it was important to give you skills to cope. And you know, the fear of you being teased was, was very difficult, but we realized we can't feel that pain for you.

Ashley: Yeah.

Janet: We, we just can't. We have to love you and be there and let you deal with the world, but to hopefully give you good skills so that you can do that.

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

- Ashley: Yeah. Yeah. Those coping skills, something that I really appreciated throughout all of this, um, is how much of an advocate you were for me. <laugh> and I know sometimes your mama bears gotta come out. Um, were there any times in particular, like one that you can think of that you really felt like you had to advocate or a time when you feel like you should have advocated more?
- Janet: Well, there probably a lot of those, uh, when you were in the hospital for one of your surgeries yeah. They put you on an adult floor. So you were still a child.
- Ashley: Yeah. For my jaw surgery,
- Janet: I think. But it was a time that was difficult at the hospital because they were short staffed and they probably put you where they had the staff.
- Ashley: Yeah.
- Janet: But they also told me that I would not be able to spend the night with you. And that just was absolutely not going to happen. Yeah. I wasn't going to leave you. And that was one of the hardest or the worst hospital experiences because of the short staffing. Yeah. And there's no way you could stay alone in the hospital because you could not advocate for
- Ashley: Yourself. Right. So you were just like, watch me <laugh> <laugh>
- Janet: I told her I was staying, she said, you bet, she said, I'm going to ask your, your roommate. And I said, well, well I ask all you want
- Ashley: <laugh> I'm staying no matter what <laugh>. So did you ever run into any insurance difficulties? Because I know there are some people with, uh, cleft or other, uh, congenital differences who are unable to get surgeries and treatment covered. Did you and dad ever run into that?
- Janet: We were blessed. Yeah.
- Ashley: So
- Janet: Blessed. We were double-covered with insurance. We never even saw an EOB, an Explanation of Benefits. Yeah. We never had a copay. We never, yeah. Nothing. You're
- Ashley: Really lucky. We were
- Janet: So lucky and I feel so sorry for people that have insurance nightmares and aren't covered, or they won't cover the care that a cleft child needs.

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Ashley: Right? Yeah. So it's, which is why that Ensuring Lasting Smiles Act is so important because in a lot of states, in Michigan, actually, where we live is one of them where it's actually not up to the, the provider, the surgeon or the doctor to determine if a surgery or treatment is medically necessary. Instead, it's left up to the insurance companies to make that decision and they get to decide whether they cover it or not. And essentially whether the child gets the surgery so

Janet: Well, and not only that, but even, even if your insurance covers it, some people have horrendous copays and deductibles. Yeah. That, so you meet it one year and then you got to go back and have another one another year and another year.

Ashley: Yeah.

Janet: Thousands of dollars, just thousands and thousands of dollars that yeah. Many people don't have.

Ashley: Yeah. So we were really lucky

Janet: For sure. We were really, really lucky

Ashley: From your perspective as a parent, like I could talk all day about what my, you know, challenging parts, you know, undergoing treatment were for me. But as a parent, what do you think was the hardest part about surgery or about watching me grow up or, you know, any of the, the journey at all?

Janet: Again, there were probably many. Waiting in the waiting room was horrific. Yeah.

Ashley: During

Janet: Surgery, during surgery, that was horrific. But also if we could have felt the pain for you yeah. That going through the surgery and the anxiety and all of that. Yeah. You know, I just said, we couldn't feel the pain for you <laugh> oh, you wish that you, but I wished I could have for the, the surgeries, it just, yeah. It was very difficult. Yeah. To

Ashley: Watch. So all of that. And then, um, what do you think was the most challenging surgery from as a parent? Like from your perspective? So whether it was like the actual surgery or whether it was like the aftercare involved.

Janet: Oh.

Ashley: Or all of them <laugh> well,

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Janet: Each in their own way. Right. Each in their own way. Yeah. You have this, this little tiny baby who's 10 weeks old and you're handing them over to be yeah. Put out

Ashley: <laugh> right. Yeah.

Janet: Yeah. And, and, but then you think, well, they don't know. And at that time, the anesthesiologist, I think anesthesiologists must have some, yeah.

Ashley: <laugh>

Janet: Some good training.

Ashley: They have a little bit more bedside manner than anyone else. Um,

Janet: But he said, don't worry, we'll take her, will rock her till she goes to sleep. We'll hold her. Yeah. Then that's one of those things that, that helped.

Ashley: Yeah.

Janet: Uh, but it was still very, very difficult. But then as you got older and the anxiety kicked in and you knew it was happening, that was horrible in its own way. Yeah. Too. And the aftercare for the jaw surgery. Yeah. It wasn't the aftercare, but how difficult it was for you to not be able to

Ashley: Eat. Right. Yeah. So they all had sort of their own mm-hmm <affirmative> things. Huh. Well, I feel like I, every time we talk about this, I learn more and I don't know if this is other people's experience, but for me, I know that like we didn't talk a lot about this stuff. And I think that that's true for probably a lot of people. And I'm just really glad that we're in a place now where we can talk about it and just getting to experience or understand like both sides and because it's such a unique experience, a unique journey. And I love that when we talk about it, it's like putting the puzzle pieces together and creating

Janet: Yes. I, I agree. And I have to say that failure as a parent was to not recognize all the anxiety you were going through and how difficult things were for you, were you played a good game?

Ashley: Well, that's what I was going to say. It wasn't failure, uh, a parenting failure. It was that I was just really good at <laugh>. I was really good at hiding it, but,

Janet: But that was, you know, learning once you,

Ashley: And I also think to some extent, a lot of what I've been processing over the last several years has actually been me learning that I was feeling those things at that

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

time as well, because it was just really hard. So like, I didn't want to think about it then. So I was hiding it from you. Yes. But I don't want you to think that I was, you know, in a corner by myself, like wishing someone would notice that I was feeling a certain way because I also, as adept as I was at hiding it from you, I was also adept I think, at hiding it for myself. That's true. So, and that has been, um, a learning experience over the last several years for me. So, but it is now time for us to take a little break. And when we come back, we'll have my beautiful co-host Iva on and she'll get a chance to talk to you and I'll be here as well. Uh, and she'll get to ask any questions that she might have about our experience and maybe how it compares to her own and, and anything she wants to learn as well. So, all right, we'll see you after break.

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 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.

Iva: Okay. Audience, I know that you are just like me and want more first. I have to say Janet, thank you so much for coming on the podcast. While listening, I was smiling so big because there were so many moments that I related to just from Ashley and I shared experience, but then also just stories that I've heard from my mom. And I do again, want to thank you for the vulnerability of crying because my mom made me cry. So it is fine. I had so many

Janet: Dreams. I don't cry

Speaker 4: Though. This she doesn't,

Ashley: My mom is not a crier. My dad and I are, will cry all day. My mom doesn't usually. So

Iva: That is the beauty of what happens when Love Meets Joy and when Smile Train brings us together. So again, I, we have to say thank you for that. But listening to you talk about Ashley and the anxiety and just the journey. I want to know. What is your proudest cleft moment for her or proudest cleft accomplishment? You know, we've talked about how we couldn't blow bubbles or we couldn't do certain

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

things and to be at the place now where we can, could you share with us what your proudest cleft accomplishment is?

Janet: You really want honesty?

Iva: I do.

Janet: I don't remember the bubbles <laugh> I don't remember. I don't remember any of that, but her advocacy right now is just amazing and yeah, I'm really proud of her, for that. And for overcoming so much adversity.

Iva: <laugh> all of it. It is, it is amazing to watch. So I think we're right along with you as like being proud of seeing that and then something else that when Ashley said it, I fell in love. But hearing you tell it, I really fell in love with you, Janet, when you said that in the delivery room, everybody swarmed to you, but you were thinking, what about my husband? This is his child too. Who's there for him? And I think that a lot of cleft dads who listen to this are going to relate because they're sometimes forgotten about that. So again, I wanted to thank you for that. <laugh> and you said that you didn't say anything, but would, if you could, what would you say to that group? Like, Hey, go get him. Or what would you say?

Janet: Absolutely. <laugh> I should have been the mama bear for my husband. <laugh> help him give him warm blankets.

Iva: <laugh> he need warm blankets too. Exactly. Because to leave him out there like that in the cold, he needed warm blankets too. And I really, I really admired that when she said that was the, your initial thought. And then something else that I wanted to know is I know that Ashley has a younger brother. Was there ever a time where you felt that you had to explain what was going on as far as all of her surgeries to him? Or was it just that's my sister,

Janet: I think that's it. I, I don't think we did additional, I mean, we talked about it and it was just a normal part of

Ashley: Life. Cause it was just how he knew me, which is interesting because I think your experience was similar, although, so Iva has a brother as well. Who's five years older. Oh. And so it's like the opposite. Yeah. But what's interesting is it sounds like he never even had a question even when she was brought home from the hospital and you know, the cleft was untreated. So

Iva: It was just love at first sight.

Janet: Well, and Michael, you had most of your surgeries before he was cognizant of

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Ashley: What was happening? Yeah. And so when I did have my surgeries, where would he go? Did he go to grandma's?

Janet: He was, he was in school.

Ashley: Oh yeah.

Janet: Okay. But yeah, probably grandma's yeah.

Iva: That's exactly where my brother would go to. Um, so we are in Florida. My grandmother was in North Carolina, so he got to spend the summers in North Carolina. And so again, that shared experience is I love Ashley and I's connection because it's so similar, but we have our differences. But one thing that I do know is very similar is a little bird. He told me that you like Frankie and Grace,

Ashley: <laugh> Grace and Frankie. We do,

Iva: My mom also likes that show and I am going to coin you guys the new Frankie and Grace because you guys are mama bear. You are mama bear. When you said that you were like, this is my child and she's good. Because my mom had the same experience of, you know what, this is my child. And did it just innately happen or

Janet: Absolutely. It just happened.

Iva: It just happened. And you were mama bear.

Ashley: Yeah. And was, was there because you said that you didn't leave for a while, was it because you were afraid of what people might say? Well,

Janet: That might have been part of it. Yeah, but it was also winter. Yeah.

Iva: Yeah. It's common not to go out with a new baby. I mean I know people who have a new baby who don't go out for two months. I couldn't imagine that I got to get up the house, but

Ashley: Yeah, <laugh>

Janet: Exactly, exactly.

Iva: I have to get out of the house. I can't do that. But how you said like, you know what, this is my baby and then something else that I really admired when you said you couldn't feel her pain mm-hmm

Janet: <affirmative>

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Iva: Did you have that conversation with your husband and say, this is

Janet: How we're going to, we absolutely had that. We had that conversation

Iva: Really mm-hmm <affirmative> because I know sometimes that again, being mama bear, you do, as you said, you want to shield and you want to absorb some pain, but you make the conscious decision to say,

Janet: Well, I'm not saying we didn't feel the pain <laugh> I said we were going to try not to feel the pain. It wasn't, it wasn't going to do any good giving her the skills, to be able to function. Yeah. Seems more important than going. Oh my God. My poor baby, my poor baby.

Ashley: So like empowering. Yeah. Empowering is important.

Janet: I think so.

Iva: And you absolutely did. I think, um, one thing that Ashley and I have talked about before is like the story that we told, but the, whenever she tells her story, she always does say that you and her father were pushing her about advocating. There are certain things that you just don't innately know, but you figure it out when it came to advocating, how did you figure it out?

Janet: Well, it it's just what had to be done the hospital. Right. You know, I'm not leaving this child in the hospital, especially when you're short staffed. Right. And putting in IVs wrong and doing all kinds of things.

Ashley: And how did you teach me how to like advocate for myself? Cause I think about how, like I would do a class presentation in elementary school who came up with that. Did you guys come up with that or did the social

Janet: Worker? It wasn't the social worker at school. Yeah. I think maybe we talked about it and I have to tell you, I was actually shocked when you decided to include a picture of an unrepaired cleft in your presentation.

Ashley: Yeah. I used to bring in baby pictures. Mm-hmm

Iva: <affirmative> so even back then. So she's been advocating is just like slowly but surely

Janet: Those presentations were amazing. They were just amazing. And I think it helped her along in school to not be teased as much and, to be harassed by the other children.

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Iva: I have said to her several time, I wish that I would have even thought about that because it is when you go in and you're saying, Hey, this is what it is. It kind of takes away that sting again, kudos to you and her father for even planting that seed and encouraging her to do that. But I also have one other little, little birdie who might have said that just like Carolyn, you have a special way of like a little specialty as far as when you make our shakes for the jaw surgery.

Ashley: I tried,

Iva: She tried and I want to let you know, from the other side with Ashley, we could always taste it.

Ashley: <laugh> well, she knew I could always taste it.

Janet: How did oh, the Ensure? Yeah.

Ashley: <laugh> so tell the people because um, I was very skinny when I had my jaw surgery anyway, so they were worried about me losing weight. So, they wanted you to give me the Ensure to make sure that I gained weight.

Janet: Right. But she wouldn't drink the Ensure. Cause

Ashley: It tasted

Janet: Bad. Throw

Iva: It in. You can always taste

Janet: It. But there are so many protein shakes. Well, especially now,

Ashley: Now, but back then,

Janet: Oh, there are so many, three

Iva: Flavors

Janet: Back then it was Ensure or what's the other

Ashley: I know. And Boost

Iva: Boost, it was Boost. It was

Janet: <laugh> or even instant breakfast. I think you like Boost

Ashley: Instant breakfast. I do like I actually still like instant

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Iva: Breakfast. I do remember the only good one was Slim Fast strawberry Slim Fast was the one that I actually,

Ashley: Oh, and we didn't need a diet drink though. <laugh>

Iva: I know, but that was the only one that I was like, I'll take that.

Ashley: And it had extra nutrients it and

Janet: It'd be one thing if it was one or two weeks, but when you're talking six weeks of liquid, not soft liquid diet that you can't even, you can't put a spoon to your mouth, you can't put anything. And in the beginning, it was drizzling with a tube and

Ashley: Yeah, the catheter tube contraption that we've talked about before and it had, so it had to be thin enough to get so like sucked up in that tube.

Iva: And so I have one last thing that I have to talk about in this part. Let's talk about the A&W breakdown or the A&W float breakdown because Ashley, I can empathize that. It's like, I just want this one thing I'm hungry. But from your standpoint, do you remember like what you were thinking when she had a meltdown over

Janet: A float? So actually there were two big meltdowns at

Ashley: A&W

Janet: At A&W they were both at A&W

Iva: <laugh>.

Ashley: That was the only place I can get any food

Janet: <laugh>. So the first one was with your dad?

Ashley: Yeah. After church.

Janet: Yeah. And we got a Brown Cow, and we told him to put more,

Ashley: A Brown Cow is ice cream and root beer mixed together. So it's a float, but blended.

Janet: Okay. So we told him to put more root beer in the ice cream while it was still too thick. So we had to keep going up and she just, she just said, no, I'm done. Yeah. I don't want it anymore. I'm done. I'm done. Oh. And my heart just broke. It, it, it

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

was, it was like, I, I can't do anything. I can't, I can't give you food. You won't eat, you don't even want the Brown Cow. Now that

Ashley: It's,

Iva: It's like the one thing <laugh>,

Ashley: It was so hard and it happened. And then the next time I think we went, I got a Brown Cow, but like, I think just going in and smelling it all, all

Janet: The food and, and whatever. And it was another meltdown over, over that. I guess we're lucky. It was only twice.

Ashley: Well, lucky it was only twice. And it was only at the A&W where we weren't anywhere fancy. Oh, the so

Iva: Great,

Ashley: Good midwestern restaurant.

Janet: <laugh>

Iva: But you were mama bear and you were going to do whatever you had to do. And I, I love that at the beginning, you said that your proudest moment has been watching her step into this newfound love and appreciation and awareness and educating for her cleft. How do you feel sometimes when you are reading something that she might have revealed that she's even revealing to herself for the first time, and you're reading it on a post?

Janet: It's difficult. Mm-hmm, <affirmative>, it's very difficult.

Iva: My mother has told me the same.

Janet: Yeah. It, it is. But yeah, it is what it is. Yeah.

Ashley: <laugh>

Iva: But you're proud that she's getting it out and that she's helping others.

Janet: Oh, absolutely. And she's dealing with her issues. <laugh> issues. Well, your issues.

Ashley: Oh, my issues. I'm dealing with them, even if it's on a public platform. <laugh>

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

- Janet: That, that was hard too, knowing that she was putting it all out there on the internet.
- Ashley: But now that you've seen it for a while, do see like how it helps people too. Absolutely.
- Janet: Yeah. Absolutely.
- Iva: Is it hard again as a mama bear because you want to make sure that it was received in the right way or that, you know, she would be protected because she's also shared some of the experiences that she's had, or that people have said back to her. And it's like, people are still very cruel.
- Janet: Absolutely.
- Ashley: Cause just it's scary. It was scary to do it myself, but then probably to watch me do it, because you didn't have control over what I was putting out there and stuff. It's probably tricky.
- Iva: My last question for you, Janet is we talked about the stories that we tell. And so as Ashley is writing this new story for herself, how do you hope that it will end? Like what, if you could write the ending of this new story of this new journey of her cleft love
- Janet: With her being happy <laugh> yeah. The, the, whatever. Yeah. With her being happy and happy with what she's doing and that it takes her in whatever direction it takes her. That is positive and yeah. Good for
- Ashley: Her. Yeah.
- Iva: I think that's a good read. And I think that will, we got that one coming
- Ashley: <laugh> I love it.
- Iva: And so now I'm going to kick it to Ashley so she can ask you another part that we really love. And I'm interested to hear your response to this.
- Ashley: All right. Here's everyone's favorite segment that we love to call Smile and Slay, where we talk about questions that we've gotten either from our listeners or that we've gotten from friends and family. So our question today, mom <laugh> is how were you able to overcome the anxiety of sending me to school? I know a lot of readers that I have. Right. And they say, you know, what was school like for you? I'm really nervous to send my daughter to school or my son to school for the first time. So how did you get over the anxiety of that?

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

Janet: You didn't,

Ashley: You didn't

Janet: Also, you were in daycare from six weeks on, unfortunately. And so that meant you were in daycare with an unrepaired cleft.

Ashley: Yeah.

Janet: Uh, and that was hard. The first daycare provider was not the best, even though she came with huge, wonderful references. Yeah. But I wasn't happy. So we ended up with overall very, very good people. Yeah. The schools were good, but the anxiety of sending you out there and, and having you face the world, I never got over it.

Ashley: Yeah. Well I think that's probably true for a lot of people. Mm-hmm <affirmative> right. And yeah, I wonder, so did it ever get easier when, as I got older at all? Well, yeah. Yeah. So it was probably initially very hard because feeding and everything was so difficult before I had any treatment. And then,

Janet: Then you were at, at a preschool, that was, they were very good with you. And I don't think there were any issues ever, uh, going to kindergarten. And I think this is an issue for even people, without any

Ashley: Differences,

Janet: Differences that you're in daycare, you get daily feedback, you hear what's happening, you know, what's going, and then suddenly you're in kindergarten and you're rushing out the door and the teacher doesn't come out and you can't go in the room. You don't know. Well, I you're used to this feedback. So you don't get the daily feedback. You get feedback at parent-teacher conferences. Yeah. Which was really hard.

Iva: Make me think of another question. Do you feel that sometimes teachers were annoyed if you asked extra questions and this, cause I know that my mother would ask extra questions, but it's like I have a child who needs extra attention. So do you feel like you ever got pushed back from teachers if you had like extra questions or concerns?

Janet: I don't think so.

Ashley: Yeah. No pushback.

Janet: Only pushback they might have said. Yeah. Yeah. Yeah. And then didn't do

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

- Iva: Anything. Didn't do anything.
- Ashley: Yeah. The only story I can think of is when I was in high school and you emailed the guidance counselor after my jaw surgery to tell them if I started choking that they had to like cut my things. Yeah. And what did they say? They weren't very responsible
- Janet: To, I, I don't know that they said anything again. I think it was a yeah, yeah, yeah. Whatever. Or, you know, to, for them to be aware that she's got this, her wall, her jaw is wired shut. Yeah. And just for teachers to please let the teachers know. To be mindful that she's got this and yeah. Uh, but I, again, I think it was more of a yeah. Yeah,
- Ashley: Yeah, yeah. But,
- Iva: And it's more than a yeah.. Yeah. Yeah. Situation pay attention to people.
- Janet: It absolutely.
- Ashley: It is for sure. Do you have any more questions, Iva?
- Iva: I think that was it. I just want to say again. Thank you Janet, for coming on and everyone that is our show for today. Thank you so much for listening. We would love to hear from you. You can find me on Instagram and TikTok at RealSophisticatedJoy.
- Ashley: And as always, you can find me on Instagram at CleftLoveIG or TikTok at CleftLove.
- Janet: Don't forget to go to smiletrain.org, to learn more about all 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 at five-star review.
- 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, 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%

Love Meets Joy Podcast
Episode 7: A Parent's Cleft Journey: Meet Janet Barbour
Transcript

free. Learn more at [smile train.org](https://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.