

NF Stories - Meet Sheena

Brandy: Hi and welcome to NF Stories Live, a show that shares people's journey of living with neurofibromatosis. I'm your host, Brandy. And on today's episode, I get to sit down with Sheena, a wife and a mother of two girls, one who has neurofibromatosis. Welcome, Sheena. Thank you for joining me today.

Sheena: Hi

Brandy: How about we start with how your daughter was diagnosed? How that all started,

Sheena: When she was little, probably like six months, I noticed maybe seven or eight months actually, I noticed that she couldn't crawl and that she was struggling a lot with with like moving around. Basically, she'd just sit on the floor and not do much else. And I felt like other people I had met with, babies at that age, were trying to learn to move and stuff. And I got concerned. But the doctor told me that I was just being, that I was worrying too much. And then when she was about a year she wasn't really trying to walk. She still couldn't crawl and and it was like she would do this like scoot sometimes and then go somewhere and pull herself up. But like, she just looked awkward when she tried to walk while holding onto things and she wasn't really talking and. Again, I asked the doctor and he told me that she'll learn on her own and that everything was fine, but by about two and a half, when I realized she could barely say like words, and we ended up teaching her sign language so we could communicate with her. I, I kind of put my foot down and said that I needed more answers and that this isn't just slow learning. I knew there was more. She was walking at that point, but she never looked like she was never very like. Balanced or I don't know. It was just

different, she was just different. And finally he sent us to your pediatrician when she was three, I believe it was. And the pediatrician sat her down in the chair and did the whole, you know, doctor checkup thing. And then she came in the office and told me to sit down. And she said, I don't want to diagnose your daughter without sending her to get proper testing, but I'm ninety nine percent sure she has something called neurofibromatosis. And at first I was like. My stomach felt sick, right, because I didn't know what it was, I'd never heard of it ever before.

Brandy: Yeah.

Brandy: And she said that usually that it's a genetic disorder that and she just explain things to us and told me that to wait till genetic testing at Children's contacted us and got her for sure. Before we got scared, like in case it wasn't that and not to Google it, but whoever tells you not to do something. You do it.

Brandy: Yeah. I did the same thing.

Brandy: So. Yeah. I kind of started there. Unfortunately, it took probably another year before we finally got the appointment at Children's and got the actual diagnosis. But through that year we were. And with having multiple appointments with the pediatrician, we are pretty sure that's what it was at that point. Yeah, we didn't get the confirmation for another year till she was probably about four.

Brandy: And so by then what you're seeing you guys already through seeing the pediatrician, we're pretty sure what other things were coming up that made it more obvious that she had NF?

Sheena: She said that one of the signs for NF were the cafe au lait spots and an enlarged head and she had an over over average size

head and she had a lot of cafe au lait spots all over her body. And we found more appeared as time went on as well. She still struggles with her speech big time. Most people couldn't understand her still. And and she was a little bit. Like I don't want to say, I hate the word slow, but she's a little bit behind socially and stuff, so it was just those things that made the doctor, the pediatrician feel like that she had NF. We did end up seeing multiple specialists. We saw the eye doctor who confirmed that she had the spots on her iris,

Brandy: OK?

Sheena: He said that that. That we would keep looking, checking them every year to see if they are causing any problems in her vision. One of her eyes was a little bit lazier than the other. We but, yeah, that was like I mean, she ended up going there. We got her into a occupational therapist and a physical therapist and a speech therapist doing that three times a week.

Brandy: So you had those supports going for her as she was growing?

Sheena: Yes. So it was it was really good to have such a good pediatrician that that helped us figure out what we could do to help her.

Brandy: Got you all set up with the right supports

Sheena: Genetic testing, really? It's funny because you would think it would be such a big like deal, hearing them say, like, yea, she has it, but I think we all knew that before we even had the genetic testing and and if we were already had so much stuff in place already that it was just like, OK, you're just we drove out here to tell us what we already knew it.

Brandy: Just check that box.

Sheena: Yeah. But at the same time, it was kind of nice to just to have that confirmation and know that I wasn't, like, diagnosing my daughter or something she didn't have. Right,

Brandy: Exactly. Yeah. That confirming of that. Yeah.

Sheena: And and I asked some questions because, like, part of me secretly for a year thought that it was something I did in my pregnancy that made it happen this way. And because it didn't make sense to me that it's supposed to be genetic and my husband doesn't have it and I don't have it and our parents don't have it. And so they're telling me it's genetic, that no one else has it, but that it just happens sometimes. Like a mutation, they called it, but. But then but there was nothing I could have done differently to make it not happen, but I didn't feel that way. So that was hard for a good year. The genetic specialists, you know, pretty much convinced me otherwise. So that was nice.

Brandy: It's nice to have that comfort knowing that it wasn't anything.

Sheena: It made me feel less crazy, too, because I know, like, it took multiple appointments just for that family doctor to send us to a pediatrician in the first place because he kept saying that I was comparing her to my friend's kids too much and that it was and that she would learn it all on her own time. But it wasn't about that. Like, I could see that she was trying and it just wasn't connecting. And and at that age, it shouldn't be that hard for her. And so I knew there was something preventing it, preventing her from doing the same things as those kids

Brandy: Yeah that mother intuition kind really kicked in. Yeah, that's really good that you advocated for that. What would you say from then to now? What has her journey been like from your diagnosis to where she is now? Has.

Sheena: Well, she continued speech therapy up until she went into middle school. We've kind of got to the point where she's pretty, like everyone can understand her now, she just doesn't have the best pronunciation with certain sounds, but but it's not significant enough that people can't understand her. So, like, we work on it with her, but she's also 13 now. So, like, what 13 year old wants to practice to pronounce certain words. But she has over the years has grown some subcutaneous neurofibromas. None of them are very big or hurt her or anything like that. They're just they look like little like moles or whatever, you know, but they're not brown under the skin. She has two tumours, though. She has one on her optic nerve, so an optic nerve glioma on her right eye, which causes it to be a bit lazy. We tried glasses for quite a few years to try and help make the eye stronger.

Brandy: OK,

Sheena: And it did help a little bit, but at this point, we stopped seeing a significant any difference, and she never like she doesn't really have problems with vision, so she didn't want to wear the glasses because she didn't see a difference in vision when she wore them or when she did it.

Brandy: OK,

Sheena: So she's pretty much stopped wearing glasses now. We still try and encourage her that it might help the eye, but the optometrist at Children's like said that that he's not too worried about it. So we're not

we're just, you know, letting her be her, but she has another new brain tumour. But it's not it's like. They called it a brain tumour at first, but we found out on her last MRI, it's actually like on the skull, not really on the brain, but it's it's not growing. So we're there said that it's OK if we wait to do another MRI for two years now instead of one year.

Brandy: Oh, that's good.

Sheena: Yeah. So so that was good news because at first they told us there was another it was a brain tumour and then they said, no, actually it's on the outside of the skull. So. That was good news to hear better. We always like make sure we watch for headaches or anything like that, right. But she's she's gotten pretty lucky in all sense of. Because like I, I've been through. I've done a lot of research on NF and I've gone to all the symposiums and whatnot and stuff, so I see how much it can affect people. So when we think about even though she has tumour's and some learning disabilities and speech issues and and it took her a really long time to do things, and we're still pretty lucky, you know, like she didn't learn to ride a bike until two summers ago when she was 10. And it still was really hard for her until this summer. So just like. At first, it was hard for me to watch her struggle with that, but now that she rides, it's say nothing, right?

Brandy: Yeah, you just keep supporting her, right? And yeah, yeah, yeah.

Sheena: I mean, things are I feel like are always going to be more difficult for her because of NF, but I just tell her. Like, just because they're harder for you doesn't mean you'll never do them. It just means you have to work harder at it than other people. And yeah it sucks sometimes. But but at least you know, you can do it. You just have to work harder.

Brandy: Yeah, exactly. Exactly. That's awesome. What would you say is her her biggest challenge right now that she's facing or that you're facing as a family?

Sheena: Puberty, no honestly our biggest challenge lately, and I wouldn't even blame it on NF it would be, it would be just her being a 13 year old girl and going through puberty and hormones right now. I think that's pretty normal with any 13 year old girl and it probably has nothing to do with NF. And I know that, like Cheyenne has sensory processing disorder. And so I think things are harder for her in that sense, too. So like, when we go for, like MRIs, she loves MRIs but then if she has to have an IV like that's really hard for her because. It's it's people have to touch her more and she just doesn't like being touched very much, you know, and being her age like she should be like. I shouldn't say she should be, but a lot of 13 year old girls are like, you know, worrying about their hair and stuff, and she couldn't care less about brushing your hair because it's never been a comfortable thing for her. So it's not like that or not exactly easy for her. But but one thing that's awesome is Cheyenne's never let anyone. Tell her how she should be

Brandy: That's awesome

Sheena: For like. Yet, like she always says, I like who I am, if they don't like it. Who cares? And so I've always been very grateful that she has that type of look on life. And I definitely find it makes it easier for her right now. Being a teenager.

Brandy: Yeah,so you haven't found anything like they say with for us women puberty or having a child with an NF can sometimes exasperate the symptoms. You haven't found anything like that for her?

Sheena: No. And that was the thing like her doctor said that, too. And we were worried that maybe like some of the tumours would grow or something while she's going through puberty. She did end up getting while she was going through probably another tumour on her foot, but it on the top of her foot. And it's just like a bubble and it doesn't hurt her. And you just find we just find that it's harder for her to fit certain shoes now because of it. So that happened while she was going through puberty. But I mean, like. It's just like a jelly bubble on her foot, it's like it's not hurting, right. So we've been pretty lucky with the very little changes that have happened besides hormonally, emotionally I should say.

Brandy: well, that's pretty good. What would you say has been your best resource that's helped you along so far on this journey?

Sheena: Well. Well, like my my paediatrician's been awesome, but I definitely think I've learned the most and felt the most like part of something or like and like I wasn't alone by going to all those those BC Tumour Foundation things we've done, like the auctions and the symposiums we did before covid.

Brandy: Yeah, that's pretty nice. When you have a community like that.

Sheena: They helped me and my husband tremendously feeling like we're part of the community. And it wasn't just us because we knew no one or and nothing out of that disorder before. So when we but somehow I don't even remember how we got in contact with Desiree. But when we started talking to her and then becoming part of the foundation and stuff, and it was a relief big time,

Brandy: You that support is I have to say, even for me, it's made a huge difference finding it right? What would what do you wish you would have known when you first started out?

Sheena: I can say that, you know, at. I was a young mom, I was only twenty three years old when I had Cheyanne and and for the first year of her life, I would get very frustrated because I always felt like I was doing something wrong. She never really learned to breastfeed properly, and we struggled with finding, she was very colicky at first, but it wasn't even colic it was just she wasn't. Like eating properly, she couldn't her palate wasn't strong enough to suck, so it took like a long time to figure out what to do to make things work. And it was a struggle. And I just maybe wish I could have been, I want to say maybe more mature and more experienced in life. So I could have helped my my baby be less, struggle less. But at the same time, no matter what age your at, I think as a brand new parent, you struggle right I don't know I just blame it o being a 23 year old mom and knowing nothing but who knows

Brandy: Yeah, you learn and grow with each, right? Yeah.

Sheena: Even if I was even if I was a 30 year old mom having a baby for the first time, it doesn't mean I would know what NF was and what to do. Right.

Brandy: Well, speaking of which, I had Tyler when I was 30 something and he was my third and I had the same thing, he wouldn't breastfeed. He was colicky. And I'm going, what am I doing wrong? And this was my third child. So it's

Sheena: I have already done this two times before what am I doing wrong with this one Yeah.

Brandy: Yeah, exactly. So you weren't alone by any means, but I know at the time you probably felt that way for sure

Sheena: Oh big time. And I didn't have a lot of friends with the kids. I didn't really have any friends with kids. I just started making them when I had the kid, I made new friends, mommy friends, you know. And so and then I started comparing my kids to their kids. And then I felt like, what's wrong with my kid? And it just it was hard. It was like. It's like being in high school again, and I was like, yeah, yes, it's not the same, but I don't know how else to explain it, but you just feel like judged all the times.

Brandy: You're not fitting in and you're not meeting those things.

Sheena: And that's how I felt in high school. So it was kind of like that. Again, I think part of me did have some post-partum I never got diagnosed, but I definitely think there was some there because I remember a lot of nights waking up and just crying as I thought I was feeling. She was just crying and I couldn't figure out what was wrong. I had know idea how to help her

Brandy: Get through that. What would you say is the most important thing you've learned on your journey so far?

Sheena: That you can't. To take it day by day and not try and predict the future o guess what's going to happen or think about all the bad things that could happen because you don't really know. You can't, Of course, when she was diagnosed, all I could think about is her being covered in tumours and never living a normal life, but I knew that if that's the way I thought all the time, she was going to get that feeling for me and I wasn't going to help her become the person she could become. And so I knew I needed to stay positive and just take

everything day by day as it came. And I am thankful that I learned that during the journey, and I mean,

Brandy: Yeah, well, it's obviously working when she's saying you like me for who I am or not. Right. So you've done an amazing job.

Sheena: So I. I don't know what I did. To be honest, I always just say to her that that I because I wasn't like that as a kid. So I always say that you're everything I wish I could have been as a kid. And I'm so proud of you. I don't know what I did to make you that way, but something good happened.

Brandy: So I think it was just that I think it was you just loving on her, right. Supporting her and letting her know that she she is just as she is right. And you love her and support her

Sheena: I did tell her all the time that you have to that who cares what people think of you. Just do what makes you happy. So that definitely sunk in

Brandy: That is wonderful advice. Wonderful advice. So one last question as we finish up here and I don't want to take up your whole evening. If you could design an NF billboard, what would you put on it?

Sheena: Like a billboard on it, on the.

Brandy: When you're driving down the road, you know, or you see those billboards,

Sheena: That's a hard one.

Brandy: Tough questions,

Sheena: Like I just every time I tell someone that I have a daughter with NF or and then they ask what NF is and when I say it, they're like, what? It's like not a single person I've ever met knows what it is unless they have someone in their family with that, which doesn't happen quite often unless I'm at a thing for it. So like, I just wish more people were aware of it, but then at the same time. When they are aware of it, I don't want them to think that they have to treat her different just because she has it right. She doesn't like to be treated different. So like she understands that she's different and she's OK with being different. But that doesn't mean you need to treat her like she's a baby or something. You know what I'm saying?

Brandy: Yeah, exactly.

Sheena: I don't know what I put on the billboard but maybe like. I don't know. Find out more about NF by. I don't know, maybe it'd be like a thing where you could give people a website to look at to find out more about it instead of judging what what they see or something. You know, because I know there's people with NF who do have a lot of cutaneous tumours and then people judge them or look at them funny because they don't understand what it is or they think it's contagious. And that breaks my heart like, oh, so much. And I, I wish people would understand more what what NF is so they aren't so judgmental and and have more understanding. I just think that everyone should know what NF is, so they're not naive or ignorant.

Brandy: Yeah, yeah. They instantly judge. Yeah very sad.

Sheena: I mean, there's always people in the world that instantly judge no matter what. But I feel like the more knowledge you have, the less judgmental you are.

Brandy: Yeah. Knowledge is power for sure.

Sheena: Yes. Maybe it could say Neurofibromatosis Knowledge is Power. And then.

Brandy: There you go. There go.

Sheena: We made a billboard together.

Brandy: Yeah. Yeah. That's awesome. Well, thank you very much Sheena for joining me today and hopefully we'll get to talk sometime soon face to face.

Sheena: Yeah, for sure. I miss our our BC Tumour Foundation events so, so much. I hope one day we can go back to doing those.

Brandy: Yes, that would be awesome. Awesome. OK, thank you. Bye for now.

Sheena: Bye