

NF Stories Live- Meet Tara

Brandy: Hello 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 have the pleasure of talking with Tara, an amazing woman who has had many titles over the years, but most importantly to her, is being a wife and a mother. Welcome. Thank you for joining me today.

Tara: Yeah. Thanks for having me.

Brandy: So you've recently your daughter's a year old now.

Tara: Yes, that's right.

Brandy: I was wondering if for our viewers if you can share the story of surrogacy and all that leading up to Sadie being born.

Tara: Yeah. So we, um, but I, I've known since I was quite young that I'm at the very least I was going to be doing IVF so we could test for NF and then when I was I had my third spinal surgery when I was 15, that's when I made the decision that I think if I do want to go with the path of having a biological child, it's going to have to be via surrogacy just because of all my back issues. And there is some evidence that the pregnancy hormones can lead to the NF tumours getting bigger and all that kind of stuff. So it's not that any doctor said, no, you shouldn't get pregnant. Although I do know, individuals with NF that have been told that, by their doctors because of where their tumours are. So that's something that the NF community should know, that it's an important thing for women with NF to discuss with their doctors where the tumours might be precarious. Sorry about that.

Brandy: It's okay.

Tara: So, yeah, once my husband and I decided that we were ready to embark on this journey, the first thing we had to do was go through genetic counseling again just to talk

to the genetics experts. And then we had to get our genetic make up basically mapped out.

Brandy: OK, OK.

Tara: So currently, as far as I'm aware, I don't think anything's changed. There's only one place in North America that actually is able to test for NF when it comes to genetics. They're based out of New Jersey, I believe. So when you have your genome mapped, you're going to do one of those little spit vile things, which I think that gives you a lot of those genetic and what not. You have that shipped off. And then they map your genome as well as your partner's genome.

Brandy: OK.

Tara: And I should mention that there is a chance that it's not possible to map your genome.

Brandy: Oh ok,

Tara: Mine was able to be mapped, but I do know other people that have had haven't been as lucky to have their genome mapped. And kind of the extra layer was that is that because I am I was a genetic, spontaneous mutation. Neither of my parents have it, so I'm the first person to have it. And that makes it actually more difficult to test. So if you happen to have a parent or grandparent and it's a multi generation thing, it's far easier. The interesting thing with that is that once you send off your embryos for testing, they use those embryos as the second generation NF markers. So the theory is that the embryos that have my identical genetic make up that are exactly the same as mine probably have NF. And the ones that have my genetic make up but are not exactly the same, likely don't.

Brandy: Oh ok

Tara: The nitty gritty stuff.

Brandy: Yeah. Did they give you a percentage of what the chances are like like they give you a ballpark or you know,

Tara: I don't remember exactly, but I want to say it was probably in the 80s or maybe in the low 90s. But again, they can't they couldn't give us a 100 percent guarantee that that if there was that she would be NF free. But they felt pretty confident saying, yes, these are the embryos that we are confident do not have NF, because they gave us the list of all the embryos that we had sent off. And I believe it was four or five of them had an NF and five that didn't. So you kind of get to that part of the journey. I don't know if anyone else watching has had experience or knows about fertility treatments, but with IVF, because I'm the female. Yeah, I had to go through the hormone injections for about a week and then they do the, um, the egg retrieval. So they take the eggs from me, took the sperm from my husband and because I was young. I was only 30 when we had that done initially and we didn't have any fertility issues. We knew we'd be pretty lucky and we actually got 36 eggs. And from that 21 fertilized egg from that 12 made it to the day five of the hatching of the cells that we sent 12 off to be tested. And then we also sent the remaining of the 21 off for testing as well, because even though they didn't survive to day 12, that would still aid them in the elimination process of my NF. The more they can send off to the clinic the better.

Brandy: Better. Oh wow.

Tara: And the 12, like I said, we had five that were free of my NF, and also chromosomally normal as well. So they were able to test for other other genetic disorders. When we got the list of what all the embryos have. We did have a few other that we had two that wasn't because they had NF. But they had other abnormalities that they were. We didn't use those ones.

Brandy: Wow, how is that like for you emotionally going through it all onto your body like with having NF like doing that hormones and the egg retrieval. What was that like for you?

Tara: From what I've heard from other women that don't have NF, I think it was pretty much the same. I, I didn't really experience anything. I think that was any different than any other woman going through with with NF. So I don't think the NF really impacted

that. And I was only on the hormones for like five days. So I think luckily that didn't really affect it at all.

Brandy: Wonderful. So that wasn't too bad. And then what was it like finding a surrogacy? Is that an easy process? Was that hard on you two?

Tara: Uh there are there are agencies in Canada that match potential parents with potential surrogates. And Canada as a whole has some of the friendliest and most optimal surrogacy laws in the world. So in Canada, it is illegal to pay a surrogate for her services. So it's purely for altruistic reasons that these incredible women are willing to give this gift to other either whether they're single people looking to start a family or heterosexual couples as well as homosexual couples, because as you can imagine, other homosexual couples that men want to have children, a lot of countries, they're not allowed to go the surrogacy route because it's legal for them. So a lot of men come here to have to have their children. The only thing that you can pay for with the surrogacy is basically reimbursing them for expenses related to their their pregnancy. So they might have if you have a woman, let's say, in Alberta or Ontario or Quebec, they might have to travel to I think the biggest clinic in Canada is Create in Toronto. So that's where a lot of people go. We used one here in Vancouver, but a lot of people have to travel for the various genetic sorry not genetic testing, umm physiological testing of their bodies, as well as doing the actual transfer of the embryo to the surrogate. We actually went through this agency and the surrogates are rigorously screened. They go through psychological testing and they get interviewed by multiple people to make sure that they're, you know, in the right mindset to be able to go through this journey.

Brandy: What was that like for you guys? Like, did you go to appointments with her or did you get to go to the ultrasounds? All that like how was that for you guys, like for you personally as well?

Tara: I really I was really grateful that I was able to do that. Like, luckily, our surrogate lives on Vancouver Island. So she came here for a bunch of the appointments and then once she graduated from the fertility clinic to, you know, to an OBGYN, she opted to go with midwives. So I would go on the ferry and go over and go with her to the appointments when whenever I could. I think there was only one or two appointments that I was unable to be there for. But that was really quite lovely and wonderful, being

able to be a part of that. And, you know, see Sadie on the Doppler and hear her heartbeat and be there for everything.

Brandy: That's wonderful. And what's it like being a new mom? How has that been for you?

Tara: It's been pretty incredible. I mean, I think we. I both felt that it was going to be something that we were both going to really enjoy and we were really keen to start a family, but I had no idea just how incredible and humbling it is to, you know, have this little human being that is completely reliant on you. And, you know, every single day she's changing and learning and growing. And it's just kind of I it's awe inspiring, really.

Brandy: Yeah. So she doesn't have any NF her she's 100 percent clear for you.

Tara: So far. I mean, obviously I know, you know, you know, things can change, but so far she does not appear to have NF. So we continue to remain optimistic that that all this genetic testing has been has worked and that, you know, she's going to be NF free.

Brandy: So how has your NF journey since the last time you spoke to the Tumour Foundation, sorry my voice, how has your has anything changed with you and your NF journey? How are you?

Tara: So I don't think anything's changed. I had my last spinal surgery. Was that 2014? So it's been a number of years now since that surgery. And since then I haven't had any new issues crop up. I continued to see my orthopedic surgeon every year just to continue to monitor things and specifically continue to monitor the area right above the last fusion, because that for me at least, that tends to be always the scary things, like watching that to make sure that it doesn't try to start to deteriorate.

Brandy: And that's all going good so far. Sorry.

Tara: It's going well. Yes.

Brandy: Yeah. Wonderful. Wonderful. What would you say has been your greatest support along this whole journey of ups and downs? For sure. What was your biggest support?

Tara: Definitely my my parents, my mom, my dad, my stepfather. And then when I started dating my husband and he was my boyfriend, now my husband, they've all been incredibly supportive. I've got a, you know, a few really great group of friends that help to support me. And my sisters have been great, as well as kind of the extended family around that. So, yeah, I feel I've been really fortunate to have a great support system around me.

Brandy: Yeah. Are you on maternity leave since having Sadie? or are you back at work or.

Tara: I'm on them. I'm on parental leave right now and that's why I referred to it as parental leave, because I technically I didn't qualify for the maternity part of the leave because I didn't give birth to Sadie. But I qualify for the parental leave and I'm supposed to be on until next July. And at this point, I haven't really decided whether or not I'm going to be going back to work yet just because me personally, with my back issues, I have found it challenging to, you know, look after her every day and not feel completely exhausted and fatigued. And I think it would be incredibly challenging to be doing work on on top of that, I think it's quite difficult to be honest.

Brandy: Yeah. Yeah and especially as she starts to get into the toddler and going and yeah, it's going to be.

Tara: Yeah She's thirteen months now and she's not quite walking yet, but she already keeps on my toes because she's a very fast crawler.

Brandy: Oh really lovely. Oh that's so awesome. Is there any words of wisdom that you would like to share with the NF community?

Tara: I think you continue to look after yourselves, you know, make sure you're doing kind of your check ins with your own like in your mind and your physical body. Just, you know like do you need something like you talk to your doctor, talk to your family just

about what it is that you need to make life with NF maybe a little bit easier. It's never going to be probably perfect, but. Try to get to that as close as you can.

Brandy: Yeah, wonderful. So I keep asking everybody this because I just I think it's neat if you were to design an NF billboard, so driving down the road you see the billboard, what would you put on that?

Tara: I think it's important to have the faces of NF because we all look so different from each other, you know, other disorders, they are kind of have like there one key hallmark or one thing that, you know, that person has this or that person has that but with NF because we all look so different from each other, because NF affects us also differently. I think a billboard that can reflect that would be, you know, important. So whether that's pictures of our faces or pictures of, you know, for example, you know, my back has been my main thing. So, you know, my back could be on the billboard with with my scars. And then someone else would be if they're if they happen to have more of the tumours all over their face and their and their body to show that, just show, you know, hey, look, look, we have this disorder that can be really scary at times and it affects us all very differently.

Brandy: Yeah, I think that'll be wonderful. Well thank you so much. Tara, you shared so much information with me today. I'm like just in awe of you and everything that you've been through. And. Yes, thank you for being on today. And hopefully we'll hear from you soon.

Tara: Yeah, of course. And if anyone who has any questions, I'm always here.

Brandy: Perfect. Thank you. Have a great day. Bye.

Tara: Bye.