

NF Stories - Meet Brandy

Desiree: Welcome to NF Stories Live. I'm Desiree Sher the executive director of the Tumour Foundation, and I'm so excited that for our first NF Stories Live feature, I get to introduce Brandy, who after this video is going to be your host for this series. But welcome, Brandy. I'm so excited that you're here and we get to chat all about your NF journey.

Brandy: Thank you for having me. I'm excited to share

Desiree: I think so many of our community probably know you and your son Tyler's story, but take us right back to the beginning. Take us back to when you were diagnosed or how when you thought something was off and you sought that diagnosis. So what was the beginning of your journey?

Brandy: The beginning was when Tyler was about four months old. He had bowing of the right leg and some what I know now as cafe au lait spots these brown spots and what's going on. Went to his check up at six months. And the doctor was like, oh, yeah, it's OK. Everything will work its way out. I'm like, OK, come back at just before nine months. And he's like, no send you to a paediatrician. He went to the pediatrician, walked into the office, barely even said, hi me and goes your son has neurofibromatosis. Am like what? what? and then you just it just mumble after that. Right. When you hear something you've never heard of before, it hits you in the face. I'm Looking at my mom. I'm holding Tyler and it just it mumbles and it was an eye opener. I went home and did what I would suggest nobody do, but everybody does anyways. And what's that? you Google. Right. And you know there are some scary stories out there. So hopefully sharing our stories will make those ones not so much, but and yeah, that was the start of us, it was the pediatrician who told us, and we

were on our way. I'm very fortunate for our pediatrician, he did right away know, with neurofibromatosis that there can be delays and he already seen it in Tyler at the nine month mark that he wasn't eating. He wasn't doing all the other things like starting to eat the foods other kids were. And so he sent us to the infant development program and that got our ball rolling of getting therapies and things like that.

Brandy: So that was a really good thing for us.

Desiree: And when Tyler entered school, what was the challenge there or were there any?

Brandy: School, we were lucky that we went to the Infant development program and then we went to the Children's Development Center and put us right into school. What was difficult was that you lost a lot of therapies when you went to school. And so that kind of was a bit of like, oh now what? So he didn't have the speech that he had regularly. He didn't none of those things were there. So I found that he lacked a little bit. But with Tyler because he had bowing of the right leg, so tibial dysplasia he was breaking all the time, so by the time he got to school, he'd already had 2 frames. He had already broken probably about four or five times. So for him, going to school at a very young age his anxiety was very high. So that was kind of a setback when he went to school. Something new again, he didn't know, was unsure. And so we did a gradual into the school. But he was always behind.

Brandy: So he had an EA right from the beginning.

Brandy: We keep going.

Desiree: And I mean, that's kind of was nine months and then entrance to school Tyler's 11 now?.

Brandy: Yes.

Desiree: And what's his biggest challenge or what's the biggest challenge you face as a as a parent?

Brandy: The anxiety and one hundred percent when you're at such a young age. And I think him having not because he's so far behind, he's 11, but developmentally they put a five year old right now he's going through an assessment again this year and hopefully we get more of an understanding. So being behind, he doesn't have that understanding where to talk to another child at a certain age. You could explain it a bit more and they may understand not that the anxiety and the scared and the fear and all that wouldn't be there, but you can kind of talk to them and work it through. Tyler, there was just no. So at a very young age, like with his anxiety. And so now we have sleep issues. We have when we're going places, there's continual questions and what's going on. And so the anxiety brings trust issues and the fear of so much out there. So I'd say anxiety is definitely taken over a lot of his life. I mean, he's got the mobility issues because learning to walk over and over again. He's got a fine motor issues, speech, like all those things. But those can be worked on. It's the anxiety that I find is what's holding him back the most because he puts a mental block for him.

Brandy: So that I would say is the biggest struggle.

Desiree: if there was a parent in front of you now whose child was dealing with anxiety, what tip would you give them?

Desiree: Is there something that's worked for Tyler that would work or you would offer to another parent?

Brandy: Slow down patience, breathe and take it easy. It may seem like you got this huge road in front of you it's never ending. Right. And to focus now, like when Tyler has a good night of going to sleep with not much anxiety. You take that and that's a win you take those little wins and try to focus on those. For Tyler we're trying to or I'm trying to teach him the breathing and I'll find it he does it now without me necessarily having to say anything. So he'll be like, you know, I'm scared or whatever and all of a sudden you will hear him. He'll go and breathe it out. Right. He is trying to calm himself down. So I think breathing is probably made a real difference because it's something that a child can take with them so I would say to try to teach the breathing.

Brandy: As for the parent, if you are calm they are calm, and I know that's easier said than done, really is.

Brandy: So if you can find practicing for yourself, that can also be beneficial. I journal. If you can take those few minutes for yourself to stop and breathe. Take a few deep breaths and focus on a few things right in front of you that can center you and ground you, I think would be really good. That helps me get through. I found when I started to be more calm going to an appointment instead of me worrying about all what can happen or things like that, If I calm myself before I go. Tyler would also be a bit more calm.

Desiree: I think our kids are always looking at us for for for clues on how to react in a situation. I love what you said just about slowing down, because I think as busy moms, working moms, we're trying to do too many things all at once, trying to meet everybody's needs. So I love that slowing down the breath work, the self care practices. And when we do those, our kids see them and we'll begin to model like Tyler is. It's so beautiful that you're giving him those gifts. Along the way, what's the best resource? I know you mentioned that infant

development program, but were there other resources that were helpful for you?

Brandy: Support. Family. When I found you guys, we found you guys very early. Our first symposium was back when Tyler was just just learning to walk. And he had been around 2 and we came and it was just really nice to find the community support, as you know. So the foundation has definitely been something that we stayed with right from the get go and having the resources and being able to talk like we are now. Right. I know with Covid we can't but to go to the symposiums and stuff like that and to connect with the families was really nice to have that support and know that you're not alone. Right. To have somebody else who, yes our journey's all look different. But we have something that we can come together and support each other. And the understanding I think that's been a really big support.

Desiree: I know you were involved with the foundation for six or seven years before you took on as part of the team as a staff role. So you do practice what you preach.

Desiree: Let me ask you, I mean in your journey, as with Tyler, has there ever been a time when a physician wanted to do a treatment maybe that you didn't agree with?

Brandy: No, I have to say, I was actually one who I almost wanted to push a treatment I wanted Tyler's leg straight so fast, I wanted. Why can't it be straight if it being bowed is making it weaker? Like you can think of a tree branch, right. It can break easier the more it's bent. Why aren't we fixing that? And it was the doctor saying, no we have to wait. You have to be patient on that part. So I have to say more I was fighting for what or bringing up and saying, well, what about this and questioning and asking for things more than not wanting

something. And so for me, it was it was the other way. Maybe others have felt that way. I don't know.

Desiree: No, I just I that question just kind of popped up because you've spent a lot of time at Children's Hospital and Infant Development Hospitals and now Sunny Hill Hospital as well. So I how do you feel or what do you do to feel part of that health care team?

Desiree: And because I know a lot of physicians don't know about neurofibromatosis, have you ever encountered a situation where you've had to educate as you laugh?

Desiree: But OK, so I'm going to take that as a yes, yes, yes.

Desiree: And so how do you do that in a respectful manner where the information that you share as a parent is welcomed?

Brandy: I think just just coming from as a parent, honestly, as a concerned parent, you're not you're not coming in with a bull like a bull in a china shop, but you're coming in from a concerned standpoint. You're coming in from this is what my son has. Let me tell you about it. Right. You can have this and this. And these are suggested treatments for it so that I can show you we've got the pamphlets and stuff like that to show them to say and explain it. If you come from more from a concerned parent, I think it is, then it would be welcomed where if you come in. No, like really harsh. I think it's just coming from more from a concerned standpoint, I think, than they look at it and take it a little bit more softer.

Desiree: That's a great tip for all those parents out there that are in that position. What do you believe is the most missed, most misunderstood part of neurofibromatosis?

Brandy: I think there are 2 for me and people that I've talked to, those who have the cutaneous neurofibromas people think they're contagious. They've got something that they're going to catch and that it's completely misleading. I mean, there's nothing that can be contagious or caught. And then the other one is that, well, is it really that bad?

Brandy: So you've got a bump here, or there? or whether they're internal or not, are they really that bad? And they are because some of ours are inoperable. Right. You can't you can't touch them and they can grow. And they you know, it's not like you can go in and remove it or you can take said medication for it. We don't have anything. I mean, we've got the one that just got approved in the States, but so I think that is misleading. They go okay so you got a? oh well, it's not cancerous. We're good to go, right? No, it's not. So I think thinking that it's not as bad as what it is like a lot of times it's not. Don't get me wrong. But I think that is the misleading part. Like, you're not that bad.

Brandy: You're okay right or its you're contagious going from one spectrum to the other.

Desiree: There's still a lot of awareness that needs to come both out in the community to build up, I think, tolerance and acceptance of people that look different as many people with neurofibromatosis do, as well as with, I think, the medical community. What is the biggest lesson you've learned on the NF journey?

Brandy: It's opened my eyes tremendously. I was just talk with my mom the other day, like before, it's not that you didn't know things were out there but NF has opened my eyes to the whole community of neurofibromatosis and that there's so many different rare diseases our there that aren't brought into the light. Right. Because what do you hear about not diminishing them it at all?

Brandy: Like cancer, diabetes, you know M.S., those type of things are huge arthritis and all those type of things.

Brandy: But then there's these little ones that are hugely affecting people's lives and there's nothing for it. So NF has really opened my mind to that and that there has to be more awareness out there. People have just got to share, like I am one that when we're out and people can see there's something different with Tyler, he wears a brace on his leg. He moves a bit different, he talks a bit different, and they'll ask, oh, what does your son have? is he okay and they automatically go to autism or something like that. And then I have to say no he has neurofibromatosis. I think that 10 seconds just to say it. You might think it might not mean anything, but it opened that door and it brings awareness. So I think just opening my eyes and the whole world that and the amazing people of neurofibromatosis. They are very strong people out there. That's all I gotta say.

Desiree: Yeah I mean, it's a little bit of conundrum around neurofibromatosis, because when we say that it is one of the most common single gene disorders, but it also fits under rare diseases.

Desiree: And when you look at rare diseases, it's one in seven Canadians are somehow affected by rare diseases, which is a huge number. But you're right, if you're not kind of the top three of heart, stroke or cancer, you just one don't get the awareness or the funding or perhaps the compassion. And I think that's the piece that we really need to work towards. Just having compassion for those that struggle with these rare disorders and especially neurofibromatosis.

Brandy: It's just not talked about its like you said, we're having to still educate. We are still learning about it at that right. So all the time

we're learning different techniques and ways to deal and cope with the condition.

Desiree: Ya, if you were going to design a billboard to increase that awareness, that's so much needed for NF, what would you design on?

Brandy: The faces as many faces as we can get out there that people are willing to share their faces for it to show the difference of NF and bring awareness to it and have some type of slogan. I don't know what it would be, but neurofibromatosis ask about it or something. Right. But it's the faces, getting the faces out there so that people are aware and can see what it is and then ask the questions and then we can educate. I think would be the best thing.

Desiree: I'm always so thankful that you share your story because you are on a variety of social media platforms, not just for the foundation, but also personally sharing your story and your one hundred percent. Right. That is the way that we are going to increase awareness, increase fundraising, increase research is by bringing NF out of the shadows.

Desiree: But from the dark to the light, let's talk about what is a memory or, perhaps a funny story or a funny moment that with Tyler and NF, is there something that comes to mind when he was in the hospital, when he was younger of loves?

Brandy: When he was in the hospital, when he was younger, Tyler loves music always has. And so brothers were watching some YouTube video or some video. And it was Bruno Mars's Lazy song, right? Monkey's head. And he loved it. And so we were in the hospital, you have the nurses, Child life and they are, is there anything that we can do to get to make it better, whatever?

Brandy: And it's like you got lazy song you know like that because of the Internet was and literally one of the child life ladies actually went and burnt the CD for him so he can have it on one of the things, because if you've ever been in BC children's, you know the wifi isn't always necessarily the greatest. And so the video would go in and out. He would get frustrated. So if he had it on TV, he could watch it over and over again. So it was really funny, like them seeing him and liking that.

Brandy: So that was really something very cute. And because Tyler, has speech delay because of the NF he would always say canna like it canna like it. So instead of I don't like it he would say canna like it. So when we were doing speech therapy and even through school, I say, don't touch that phrase, because we love it and something that made like made Tyler Tyler.

Brandy: So it was just really cute.

Brandy: No matter what we would do, he would be I canna like it. It had to be like one of his first words was I canna like it. So that's one thing that we take with us.

Desiree: That's great and I think that just really hits on just NF is just another special characteristic of of Tyler, right.

Desiree: Just and I love just that your Instagram stories where he's always dancing or kind of swaying to music. That's a really big part of his life.

Brandy: He loves music, something he can do right now and keeps him going and energized and moving to,

Desiree: Ya dance party time.

Desiree: Yeah, exactly. very nice.

Desiree: I'm so grateful that you were willing to be the first NF story Live, so grateful for all that you do for the foundation and for families. Any final last words before we wrap up?

Brandy: Well, don't give up. Don't give up. Keep pushing forward. There's like you said from Dark to light, you will have your bad days, but focus on the good and keep pushing forward. And we're here. You know the NF community is here. You ever want to talk? Like we say, no one walks alone, right? So just know that you're here.

Brandy: We're here. We're all together. And just one day at a time just one day try not to think to far fun ahead.

Desiree: That's awesome.

Desiree: Breathe.

Desiree: That is a great word to leave all of us with not just our kids, but also as parents and anybody else watching take that time to slow down and to breathe.

Desiree: Thank you, Brandy. I look forward to seeing you back at the office. But in the meantime, thanks for being here and sharing your story.

Brandy: Thank you so much, see you all later, bye.