

NAME

<https://youtu.be/AUBPyLg-RDA>

DATE

February 12, 2021

DURATION

15m 56s

2 SPEAKERS

Brandy

Tammy

START OF TRANSCRIPT**[00:00:05] Brandy**

Good morning and welcome to NF Stories Live, a show where people of all walks of life get to share their journey with living with neurofibromatosis. I'm your host, Brandy, and on today's episode I have the pleasure of talking with Tammy. She's a single mother of three who loves art and animals as well as shares a diagnosis of neurofibromatosis with her three children. Hi, Tammy. Thank you for joining me today.

[00:00:30] Tammy

Hi.

[00:00:32] Brandy

So I always like to start at the beginning, it's the best place to start. So how about you tell us how you were diagnosed or when you first noticed you had NF.

[00:00:44] Tammy

I had growing up with a plexiform tumour above my right eye from childhood.

[00:00:50] Brandy

From childhood?

[00:00:55] Brandy

Was it a family physician who diagnosed you? Was it a specialist?

[00:01:01] Tammy

I don't remember ever seeing a family, just our local family physician, but I don't remember being diagnosed with it, just knowing that I had it.

[00:01:12] Brandy

OK. What was it like.

[00:01:13] Tammy

Not really knowing what it was at first.

[00:01:14] Brandy

What it was at first, it was just just a part of you?

[00:01:20] Tammy

Yes.

[00:01:20] Brandy

How was how is it growing up?

[00:01:24] Tammy

I was a bullied growing up. So.

[00:01:27] Brandy

That must have been pretty hard.

[00:01:28] Tammy

Bullied for looking different.

[00:01:30] Tammy

Yes.

[00:01:33] Brandy

Did you have any support sending things like that that helped you get through your your growing up years?

[00:01:42] Brandy

No, no.

[00:01:44] Brandy

So, no support at all. Did you, was your family supported around you?

[00:01:49] Tammy

No.

[00:01:51] Brandy

You were all on your own on that one?

[00:01:55] Tammy

I was basically on my own on that one, my mom had an NF and my grandma and my aunt and my 2 uncles don't have NF

[00:02:03] Brandy

Don't have NF, So it runs in the family. You weren't spontaneous.

[00:02:06] Tammy

Yeah, yeah. No, no.

[00:02:10] Brandy

So you live up in the mountain area?

[00:02:13] Brandy

Right I am I correct on that?

[00:02:15] Tammy

Yes I live in Lillooet BC.

[00:02:19] Brandy

Nice. And you have three kids right?

[00:02:20] Tammy

Right in the mountains right in the valley.

[00:02:23] Brandy

Nice. Yes.

[00:02:25] Brandy

Well, so with NF, we hear that things can increase during puberty or when you have for us women when we get pregnant. Did you find any your symptoms increased during those periods?

[00:02:40] Tammy

No.

[00:02:41] Brandy

No You were totally fine?

[00:02:42] Tammy

I had no, yeah I was totally fine.

[00:02:46] Brandy

That's nice. That's a good thing that is a bonus. So with your with your three kids, what does NF look like for them?

[00:02:56] Tammy

My daughter, she has speech problems and learning disabilities, the same as the other two. My oldest son has a tumour on his knee and my youngest has a plexiform on his neck.

[00:03:11] Tammy

which is connected to his cranial nerves, too. So.

[00:03:16] Brandy

What type of treatment or support have they had growing up?

[00:03:21] Tammy

IEPs in schools, and then for 17 years, back and forth to Children's, with the youngest.

[00:03:28] Brandy

With the youngest, so the other two are?

[00:03:30] Tammy

odd specialist.

[00:03:32] Brandy

So your other two are they?

[00:03:33] Tammy

They've seen the odd specialist specials.

[00:03:37] Brandy

So are they just mainly followed by the family physician?

[00:03:41] Tammy

Yeah, its my youngest that is back and forth the Children's

[00:03:46] Brandy

what's that like,

[00:03:47] Tammy

Constantly

[00:03:48] Brandy

I was just going to say, is that challenging? Like, what do you guys how does that work for you?

[00:03:53] Tammy

It was challenging, especially after the Shriners stopped running for us. It got challenging. And then I got connected with Hope Air and. Gets us down there.

[00:04:03] Brandy

Oh, so you guys fly in?

[00:04:06] Tammy

We fly in now through Hope Air.

[00:04:08] Tammy

Nice. That must be pretty exciting?

[00:04:13] Tammy

Yeah, it was it's different than the bus when we took the Shriner's.

[00:04:16] Brandy

Yeah, that must have been more of a long haul with the bus.

[00:04:21] Tammy

Yeah, it was, yeah, did you guys have any? but flying gets us there quicker?

[00:04:27] Brandy

How do the kids like flying over the bus?

[00:04:32] Tammy

Uhh he loves it cause we are there faster and all that.

[00:04:37] Brandy

Oh, that's nice. Any any funny moments or any neat things that you seen when you guys were flying overhead.

[00:04:45] Tammy

Not really, just rain, just the clouds and all that, I guess you would say,

[00:04:51] Brandy

Yeah, the beautiful scenery of B.C?

[00:04:55] Tammy

Yeah, yeah. And also we got a chance to ride in a small plane and my youngest got to take the controls a little bit. So that was a fun moment for him.

[00:05:06] Brandy

That's awesome.

[00:05:09] Brandy

When do you have any doctors or specialists that have really impacted your guys NF journey?

[00:05:19] Tammy

Dr. Armstrong from Medical Genetics.

[00:05:22] Brandy

Medical sciences is that through B.C. Children's?

[00:05:26] Tammy

Yes,

[00:05:27] Brandy

Yes. Is that the what do you see him on a regular basis?

[00:05:32] Tammy

We haven't seen her for a while, so,

[00:05:37] Brandy

When you when you come into Children's what normally is like your appointments for when you guys come down because you say you come quite often.

[00:05:47] Tammy

ENT, oncology and plastic surgery.

[00:05:53] Brandy

When you come down, do you come for all of them at the same time or are they spread apart?

[00:05:59] Tammy

We we book everything all at the same time. And then to that too we also see the eye specialist once a year. But they're all we make. We make sure they're all booked at the same time to make things easier on me.

[00:06:13] Brandy

Yeah, exactly. Are you all are you all done in one day?

[00:06:17] Brandy

Do you guys are you guys here for?

[00:06:21] Tammy

Usually it's usually spread apart. yeah.

[00:06:24] Brandy

So are you down.

[00:06:29] Tammy

Yeah, we get our like our MRIs, and then we go to the oncologist and the view and see her, the youngest also has a glioma in his brain. Oh, so he is totally hearing impaired.

[00:06:41] Brandy

Wow. Wow, that must be really tough. How do you support your son through all this?

[00:06:48] Brandy

While taking care of yourself?

[00:06:53] Tammy

We try and give each other a little bit of space or down there just so kind of breathe and whatnot you take for him, so he plays video games, so that helps calm him down.

[00:07:07] Brandy

Get some get some through the appointments?

[00:07:10] Tammy

Yeah. Yeah, that's right.

[00:07:13] Brandy

So right now, are you home schooling? Does your son go to school?

[00:07:19] Tammy

Yeah, we're home schooling. He had been through chemo for weekly chemo for a year and a half for the brain tumour. So we decided the final year school we would home school with covid and everything.

[00:07:34] Brandy

How is that going? How do you guys manage with that?

[00:07:36] Tammy

It's just pretty good. He only has his English to do so. It's pretty easy.

[00:07:43] Brandy

It's pretty easy. You guys get through it pretty good.

[00:07:47] Tammy

Yeah, we get through it.

[00:07:48] Brandy

How's it like being a mom and a teacher?

[00:07:52] Tammy

It's challenging on that part with the some of the English subjects he has, stories he has to write, its challenging, as he puts it, as grade school stuff. So some of the topics they want him to write on.

[00:08:07] Brandy

Yeah, well, I'm glad that you're there to support him. In our other discussion, you had said that you like art. What type of art do you like to do?

[00:08:18] Tammy

I do acrylic and watercolor painting.

[00:08:22] Brandy

Do you paint certain things or things like flowers, scenery?

[00:08:28] Tammy

Flowers and whatnot.

[00:08:30] Brandy

Nice.

[00:08:31] Tammy

I used to paint Orca whales for a while.

[00:08:34] Brandy

Oh, I love Orcas. They're like my favorite, so that's pretty awesome. You also said you like animals. Do you have any animals of your own?

[00:08:44] Tammy

We have three cats and two dogs.

[00:08:47] Brandy

Oh, nice. What's their names?

[00:08:51] Tammy

Scooter Garfield. Kitcha and Checa. And Sasha.

[00:08:56] Brandy

Oh, awesome. I like that Garfield. I remember that show when you were growing up, very nice.

[00:09:02] Tammy

Yeah, it's my youngest cat, his cat's been with him through all the his chemo so they're pretty close knit.

[00:09:08] Brandy

Oh that's nice. So he has the cat as a companion. That's very nice. Comforting, I'm sure.

[00:09:13] Tammy

Yeah,

[00:09:15] Brandy

That's wonderful. So with art, if you were to create a billboard, what would you put on the billboard?

[00:09:27] Tammy

Probably people of all races and belief systems all standing together.

[00:09:36] Brandy

Oh, that would be beautiful that would be beautiful. I wonder if you can do that and your acrylic painting, that would probably be absolutely beautiful. You said that you like colors.

[00:09:47] Tammy

Yeah. I am not too good at drawing people, but

[00:09:51] Brandy

that's OK.

[00:09:52] Brandy

That's OK. So living up in a town like yours, what's it like to get around for supports or with a NF? How do you guys manage in a small town?

[00:10:04] Tammy

It's pretty hard because our GP's won't let, refer you to the specialists we need to see because they say you clinically don't have nothing wrong with you.

[00:10:14] Tammy

So they won't refer to the specialist like me with me NF affected my bones, but they won't refer me to the bone specialist.

[00:10:23] Brandy

Wow. Wow. That must be really trying.

[00:10:27] Brandy

Is there a.

[00:10:29] Tammy

I grew up with multiple breaks on my legs and then my arm twice and I found out recently I have a bow in my long arm bone. It is bowed.

[00:10:40] Tammy

So which I never knew until one of the doctors at Children's happened to look at one of my x rays and he seen the bow in my arm that it's not straight like it should be.

[00:10:51] Brandy

Yeah. Oh wow. That must have been really challenging. How did you get through? Did you break while you had your kids or when you were younger?

[00:11:00] Tammy

No, I when I was younger and then when my youngest was a baby, I broke my ankle walking.

[00:11:08] Brandy

Oh, wow. That must have been challenging. How did you get through that?

[00:11:14] Tammy

With a wheelchair in the house and the kids would pushing, pushing me around, having fun.

[00:11:19] Brandy

Oh, there you go. So you guys made it fun, thought we kind of became part of it. That's awesome. Do you have you have any supports in your community, any friends that help gather around you?

[00:11:32] Tammy

With my son being in chemo, my church gathered around me.

[00:11:35] Brandy

Oh, that is awesome. That's awesome. So you do.

[00:11:38] Tammy

Yes. Oh yeah. They even drove us to our weekly appointments.

[00:11:44] Brandy

Oh, that's wonderful.

[00:11:45] Tammy

Every week.

[00:11:48] Brandy

That's wonderful to hear that. It is nice to have the support and know that you have somebody there for you. Yes. Especially being up there when there's not not very much up there.

[00:11:56] Brandy

Beautiful scenery, though,

[00:11:58] Tammy

Yeah Because we're two hours away from Kamloops.

[00:12:01] Tammy

So we got to know the road pretty well.

[00:12:04] Brandy

I bet every turn nook and cranny. Do you have any funny moments that have happened on your journey with NF?

[00:12:15] Tammy

When we were in our ENT office, my son pointed out that the intern that was student doctor only had shaved part of his mustache off and he pointed it out to him. And then before his surgery, he asked our plastic surgeon, Dr. Courtemanche, why do boys have boobs?

[00:12:35] Brandy

Kids do say the darndest things. Don't they?. And did the doctor have anything to say in regards to any of that?

[00:12:44] Tammy

Yeah, he said he can't answer that one right now.

[00:12:50] Tammy

Yeah. Student doctor, you have him covering up. Yeah. The student doctor, he had them covering up his face.

[00:12:56] Brandy

He must have been in a hurry that day.

[00:12:59] Brandy

Oh, that's wonderful. That's wonderful.

[00:13:03] Brandy

So if you were to meet a new family, newly diagnosed, being a single mom with NF and raising three kids, you've done an amazing job. Is there any words of wisdom that you would give to them?

[00:13:20] Tammy

I definitely think when it comes to the education fight for their education. Yeah, yeah.

[00:13:26] Brandy

So you find that your your kids, you've had to fight for their education to get the support that you needed to fight with me.

[00:13:37] Tammy

My mom never really fought for my education, so I made sure I'm fighting for my kids education.

[00:13:42] Brandy

That is awesome.

[00:13:43] Tammy

Make sure they get their Dogwood, they can get it and whatnot.

[00:13:47] Brandy

Wonderful. Wonderful. And you are such a strong lady. I tell you, major inspiration. You have everything you've been through. With your kids, so the other two aren't followed. How about for yourselves, are you followed regularly? Do you see any specialist? What's it like for you being an adult with NF?

[00:14:11] Tammy

The only specialist I seen was the eye specialist and my I have a really good eye doctor, make sure I see the eye specialist every year.

[00:14:22] Brandy

So you're followed and monitored for that. That is wonderful.that is wonderful, .

[00:14:31] Brandy

Have you ever had to undergo any treatments like your son has had chemo and things like that? Is there any treatments that you've had to undergo for NF?

[00:14:38] Tammy

And I went through.

[00:14:43] Tammy

Lots of operations on my eye and my jaw reconstructed.

[00:14:47] Brandy

Wow, how how was that? Did you have your kids at the time? How did you manage that?

[00:14:55] Tammy

No, I was a teenager at the time and with my eye, my mom looked after the kids while I had my surgeries on my eye, The last two surgeries I had on my eye my mom looked after the kids.

[00:15:07] Brandy

That's wonderful. That's wonderful.

[00:15:10] Brandy

Well, Tammy, I am so glad to have shared your journey with everybody here today, with everything that you've been through, the travel to raising your kids, to the amount of things that you have gone through. I am honored that you sat down with me and thank you for sharing and hopefully will be able to touch base again and see how you guys are doing in a few years. So thank you Tammy for coming on the show.

[00:15:42] Tammy

Yeah.

[00:15:44] Brandy

Have a wonderful day. Bye, everybody.

[00:15:47] Tammy

Yeah, you too.

END OF TRANSCRIPT



Automated transcription by Sonix
www.sonix.ai