

NAME

<https://m.youtube.com/watch?v=pUeHeZrpWmU>

DATE

February 12, 2021

DURATION

19m 7s

2 SPEAKERS

Tammy

Brandy

START OF TRANSCRIPT**[00:00:04] Tammy**

We got to go down in March.

[00:00:06] Brandy

You got to go back in March.

[00:00:09] Tammy

Yeah, Ben's getting his little bit of his jaw done and his wisdom, teeth taken out.

[00:00:15] Tammy

Oh, and a sleep study.

[00:00:17] Brandy

Oh, he's not sleeping very well.

[00:00:21] Tammy

Yeah Doctor Hukin figures he needs to go for another sleep study just to check everything,

[00:00:26] Brandy

Oh ok,

[00:00:27] Tammy

Make sure he's still because the way the tumor is, it's also made his throat smaller.

[00:00:31] Brandy

So she's worried about breathing issues while he's sleeping.

[00:00:37] Tammy

Yeah. Oh, wow. He's had his adenoids taken out of his tonsils all taken out. Oh, wow. We're just doing another follow up.

[00:00:48] Brandy

Well, that's good that things are being monitored.

[00:00:50] Tammy

Yeah, because I know on his wisdom teeth... I'm a little scared on that one because my youngest, oldest, when he went in for his the doctor knew about NF but never actually dealt with a patient about it. And there is a tumour in there and he severed his main artery. Oh my. Which made another operation. Yeah. They had to block off the artery.

[00:01:12] Brandy

Oh my goodness. That must have been terrifying.

[00:01:15] Tammy

He lost a lot of blood. It was I was down there by myself and. Oh, I had nobody to turn to.

[00:01:23] Brandy

Oh my goodness. I am sorry for that. My heart breaks for you. Yeah.

[00:01:29] Tammy

Yeah. It was scary.

[00:01:32] Brandy

Yeah. So I can see why your hesitatnt.

[00:01:34] Tammy

Had to go. Yeah.

[00:01:36] Tammy

And then when he had my son, when he had to go in to get his port put in and his brother had to go, he was having surgery, having the veins all fixed. So their dad came down with me, well with the oldest to Vancouver General since that's where all the equipment was to get that all fixed. And then they had to transport my son back to Children's Hospital for ICU, but they were both in surgery all at the same time.

[00:02:04] Tammy

Oh, so I was kind of. I was up and down both stairs.

[00:02:09] Brandy

Oh, I bet.

[00:02:10] Brandy

I was checking him, I was checking him out in ICU and my other son upstairs and taking pictures because they were both OK. Yeah.

[00:02:21] Brandy

Oh my. There's a lot to take on in one day.

[00:02:25] Tammy

Yeah.

[00:02:27] Brandy

But they both came out of it. They're doing fine?

[00:02:29] Tammy

They both came out of it. My oldest had his vein all rerouted and everything but yeah.

[00:02:37] Brandy

And that's all healed and everything's good on that aspect?

[00:02:41] Tammy

Yeah it is all healed, it is all normal, except for the damaged nerves in his one chin area here, but also good but the only problem is he is having all this with his teeth and the dentist not really knowing the NF and how the NF affects his teeth it is pretty hard explaining that to the dentist and they don't and then they disagree with everything.

[00:03:05] Brandy

Yeah, so you're having to advocate to teach them about NF and because they don't know anything.

[00:03:11] Tammy

Yeah. We have this new one. She's good but she still doesn't know, doesn't understand how NF affects our teeth so. Yeah its pretty interesting.

[00:03:23] Brandy

Yeah, you're educating you're the doctor and she's a student when you're there, I bet hey?

[00:03:30] Tammy

Yeah, that is pretty hard to especially when we have students coming in from UBC and they've never heard of NF But they've heard of our special concerns and Dr. Armstrong said well she is one of the professor at the university she teaches on. How do you kind of not know?

[00:03:48] Brandy

Yeah, exactly, yeah. Well, I'm glad that the students are coming in and learning to hopefully be able to carry that further. Yeah. So I'm glad that you're you're advocating.

[00:03:59] Tammy

We had one doctor who knew about it, but I was getting a small tumour off my arm, so I let him come into the into the clinic room and watch our one doctor take a couple of things off.

[00:04:12] Brandy

Oh, that's wonderful timing that is wonderful.

[00:04:16] Tammy

Yeah, and normally you don't do that, but, yeah, anything to educate them, I'll let them take a look.

[00:04:23] Brandy

Yeah, exactly,

[00:04:24] Tammy

I also had Yeah. I've also had a plastic surgeon tell your GP it hurts and they'll take it off and I don't have to pay and it will come off medical. He said lie and say they hurt because he doesn't agree with medical it coming out of your own pocket just lie. He goes what are they going to do to you, start poking you? Yeah. So I'm just saying they hurt and they are just taking them off.

[00:04:50] Brandy

And you don't have to pay for it?

[00:04:53] Tammy

And I don't have to pay for it. So I worked my way around that system.

[00:04:57] Brandy

Yeah, that's really good. Yeah. I don't think it's right when like this isn't something like I don't, I don't consider this cosmetic surgery at all for people with NF. Yeah. You know it just. Yeah. Well hopefully we can get that ball rolling and be able to do something like that for our community would be really, really beneficial. I'm glad they found a way around it.

[00:05:21] Tammy

Yeah, and that was all from a plastic surgeon who told me to say.

[00:05:25] Brandy

That's was pretty awesome. That's pretty awesome. and how are your other two managing? Just Ben's in school now or are the other in school?

[00:05:35] Tammy

My daughter graduated two years ago, so and she just got a job, so just kind of working through the anxiety because she's not a people person So too many people will bring on anxiety.

[00:05:50] Brandy

Is she doing anything to cope with that?

[00:05:54] Tammy

So it's been interesting.

[00:05:57] Tammy

And then my son my son has a YouTube channel and does scootering stuff, so.

[00:06:02] Brandy

Oh, really? That's pretty awesome. That's kind of neat that he's gotten into that. What? What. Yeah. What prompted him to do YouTube?

[00:06:13] Tammy

Yeah, he started seeing everybody else to do it, so he does that and whatnot. See Yeah.

[00:06:32] Brandy

Do they all live at home with you still?

[00:06:34] Tammy

I am very proud of them all. I'm very proud of them all.

[00:06:38] Brandy

Oh, I bet. I bet. Well, they've had an amazing mother teach them along the way. Look at you. You know, you've come very far. I like yeah, I am like honestly, I'm so honored to have been able to sit down and talk with you twice now, which has been lovely and to get to know you because otherwise I wouldn't have I wouldn't have ever met you. So thank you. Tammy like really thank you.

[00:07:04] Tammy

Yeah. I've never around here. I don't have really have anybody with NF to talk to so it's art.

[00:07:13] Brandy

I bet, you've been on one of our support calls before, right? The group chats. Have you been on those ones once a month?

[00:07:20] Tammy

Yeah, yeah, yeah. I know. I only have been on it once. I don't get the links for once a month.

[00:07:27] Brandy

So so it's on on Facebook now I usually the week of or the day before like the day of I'll post it and now there's no registration needed. Now you just click on the link to join that evening. So if you watch for that.

[00:07:45] Tammy

Yeah I don't do Facebook very often. I'm more on Instagram now,

[00:07:51] Brandy

Ok Instagram, on our profile. There's a link tree link. If you click on that, it'll say support. It will say support group meeting and the link will be right there for you. We would love to see you there. The last Tuesday of every month now, so it would be lovely to have you.

[00:08:13] Tammy

I should write that down.

[00:08:14] Brandy

Yeah, so this month it'll be on the 24th.

[00:08:19] Tammy

Yeah because I was going there for a while when covid hit bad So,

[00:08:23] Brandy

Yeah, it's nice to have a support group, especially of those who like like we said, each journey is different, but we still have some commonalities. Right. So it's kind of nice to have somebody else who may have been down that same path and had the support.

[00:08:39] Tammy

Yeah it would be nice to know someone who has dealt with it in the bones and what they do for their bone health because some days it feels like my legs broken again.

[00:08:45] Brandy

Really, really. And there's no way the doctor won't even do an X-ray for you?

[00:08:53] Tammy

They'll do X-ray's, but they won't let me see the specialist but you can see the NF in the bone. Because I remember with my daughter and she sprained her leg I had to point it out to the doctor like I could see the spots and they were actually shocked that I could read the X-ray, but I see my bones and I know what to look for. Like that is markings on the bones are signs of NF.

[00:09:15] Brandy

So afraid for my son, Tyler, he is going for bisphosphate because he broke his femur twice in less than a year and they said that like to be taking vitamin D or drinking the milk or the yogurt, the cheese. So if you could try going to the grocery store, maybe getting vitamin D supplements and taking that I don't know the exact dose might help. I don't I don't know. I'm grasping at straws like you. My son asked for cheese or milk, and I'm like, here you go. Here you go. Anything to maybe help increase that bone. but yeah. I just wish that there was somebody out there who would listen to you and let you be seen by a specialist that may be be able to help a bit more with your bones. It's very frustrating.

[00:10:09] Tammy

Yeah, cause my mom also had osteoporosis, so it took a fight for me to get some bone scans done and that's when they found out the arthritis in the hips and the tumour in the hip and with the medical genetics helping me get my disability support through PWD that's what did it, because she took pictures of everything and I also have a couple of small tumours on my sciatica.

[00:10:40] Brandy

So have you found that you've gotten more tumours as you've you've grown like, I'm just wondering because like like I said, my son is spontaneous. I don't know. Like were these there from the get go or have you gotten them as you've aged?

[00:10:56] Tammy

I lucked out I got a few of them, but if you look in the sun, you can see them. If you hold if I hold my arm just right, I can see them just under the skin. Well, I lucked out, and I don't have as much as my aunt. My aunt was worse than my mom and I think she's worse than my grandma in her complexion. Yeah. And she's a heavy smoker so I'm wondering if the smoking is contributing to the tumours.

[00:11:20] Brandy

Oh, maybe. Maybe it's definitely possible. Have you found that it's gotten worse over the years or it's been just a gradual.

[00:11:29] Tammy

Gradual, I'm lucky, so I count myself lucky, except for the ones around the sciatic and the spine, I don't count that lucky because it hurts, especially if they get bump wrong. It's like I'm floored I can feel it down to my leg,

[00:11:47] Brandy

Like it goes right through?

[00:11:50] Tammy

It goes right through. Oh.

[00:11:55] Brandy

You need bumper pads all around your house.

[00:11:59] Tammy

and I got a couple on my feet, which I won't let anybody put a needle in the bottom of my foot ever again unless I have to.

[00:12:06] Brandy

Yeah, yeah. You didn't have a good experience with that before?

[00:12:13] Tammy

No I've had one removed off my feet right, my left foot and the needle going into the bottom of your foot, that does not feel very nice.

[00:12:21] Brandy

Well, I bet not when you've had them removed Tammy have they grown back?

[00:12:27] Tammy

No, I have lucked out and that hasn't happened just on my eye because it's a plexiform and. And it almost looks like there's a tumour on top of the tumour now.

[00:12:38] Brandy

Oh, OK. So two separate ones?

[00:12:41] Tammy

Yeah, it looks like there's another tumour growing on top of the one I already have, but it's so much scar tissue now, I can't tell anything apart anymore? I've had so many operations. The next one, I might not be able to blink anymore. Oh, no, yeah it might be probably. Yeah, it's all scar tissue might be permanently closed or permanently open and I don't want that, and I really don't want to go to another operation like that again. It's not worth the pain.

[00:13:13] Brandy

The recovery is worse than dealing with it on a daily basis?

[00:13:16] Tammy

yeah and there's a 50 50, I don't want to take that chance.

[00:13:21] Brandy

Yeah, you weight it.

[00:13:23] Tammy

Because we were it was yeah, ya were given the options for the plexiform on Ben's neck to go on chemo, the new chemo that they're trusting and it's a 50 50 and it's not worth chemo again and all the side effects from the oral chemo. So he said, no to that. We would rather not fight the tumours with more chemo.

[00:13:47] Brandy

Yeah, the side effects are worse than just. Yeah, but they're going to monitor the tumour on a regular though,

[00:13:58] Tammy

Just keep monitoring it and go from there. But he was pretty firm on saying, no,

[00:14:06] Brandy

You got to respect him.

[00:14:07] Tammy

But still on the, it's still on the trial basis and so still and I don't want to be a guinea pig.

[00:14:14] Brandy

Yeah. Yeah.

[00:14:16] Tammy

And neither does he.

[00:14:19] Brandy

No exactly. So is that the one that was just approved from the FDA selumetinib . Yeah, yeah, yeah. And all the side effects, if you read all the side effects that you get, the stroke, heart attack, yeah, I kind of don't think so.

[00:14:37] Brandy

Wow, that doesn't sound.

[00:14:39] Tammy

Because we we watched my mom go to the oral chemo in and all the chemo for bone cancer than breast cancer, and it wasn't it wasn't, Before she passed away, the cancer went into the brain, so.

[00:14:56] Brandy

Oh my goodness, it's just it just went through her whole body.

[00:15:00] Tammy

Yes, she beat the breast cancer and than a year later bone cancer hit.

[00:15:08] Brandy

Oh my yeah. My my mom just got diagnosed this past year with colon cancer. And so I'm hoping that she beats it. They got to remove from the liver now. So it's it's a scary thing and then to add NF on top of it, it's gotta be just crazy.

[00:15:29] Tammy

Yeah. We were back because we. Christmas Eve, she ended up in the hospital with pneumonia and heart failure and then came home April, she was in the hospital and I had to have their dad back up saying she can't come home like she needs to stay in the hospital and they think she can walk out, that she was falling down to had to have backup and say she can't come home. Yeah, so and then I had one of the other nurses backing me up because the doctors were going to send her home and I was still doing chemo treatments with Ben back and forth.

[00:16:08] Brandy

No way, that's way too much is too much. Wow, yeah,

[00:16:17] Tammy

It was quite a lot for me.

[00:16:18] Brandy

I was just going to say, like, wow, like I would have, like curled up in a hole And here you are smiling and striving.

[00:16:28] Tammy

Yeah before my youngest could diagnose my husband we separated and that's when my son got diagnosed with the brain tumour and chemo. And I was going through all of that with my mom and I was just on a whole loop.

[00:16:42] Brandy

Oh, my goodness. Like, I like look at you, like you just you are the utmost of, like, overcoming and thriving and like, wow, I am like you're an inspiration because, like, I look at your life and I have nothing to complain about. I got nothing like you have like wow, sorry. I'm just like, you're amazing.

[00:17:07] Tammy

Ya I know, I know everybody's complaining about covid and being, you know, saying they're in jail it's like you don't know what it's like to you have gotta take chemo and you can't really socialize with anybody. Yeah. Don't have much to complain about because you can still go outside and go for walks and see people.

[00:17:25] Brandy

Yeah, yeah.

[00:17:26] Tammy

We are isolated homeschooling with the chemo and going to school for a little bit of socializing and coming home. And that's kind of what life was like with the chemo.

[00:17:39] Brandy

And so now are you home, like all the time now? No school whatsoever.

[00:17:46] Tammy

Yeah no school whatsoever homeschool, and then I just go out to the grocery shopping, see people say hi, but other than that, it's just we stay home and I go for walks and I see people. So it's not like I'm totally isolated.

[00:17:58] Brandy

That's OK. It's nice to kind of get outside. Fresh air always helps, doesn't it?

[00:18:03] Tammy

Yeah, well, the government doesn't say you're not allowed to go outside and talk to people, so I still go outside and whatnot.

[00:18:10] Brandy

That's nice. That's nice. I'm glad that you have that. That's really good. Well, I guess I can let you go now. We've we've talked. It was so nice to talk to you, Tammy. And I really I really hope that we will see you on one of the support groups at the end of the month. It would be great to hear from you and share your story and just, us be there for you as much as you are there for for us would be wonderful OK, you've got my email any time that you want to talk because you're looking at your four walls just send me an email. I'm here. I look at my four walls too.

[00:18:52] Tammy

All right? Yeah.

[00:18:59] Brandy

Bye we will talk to you later.

[00:19:02] Tammy

Ok Bye.

END OF TRANSCRIPT



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