

**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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