

Sonia and Jamie

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[00:00:00] **Jamie:** [00:00:00] That's the most important is hope- and it's somebody to keep waiting and praying. Because you don't have to be a religious person, just to wait for a miracle.

[00:00:09] Miracles are very simple thing. Miracles happened when something in the middle of the time stop right there. And when that stop happens, tell me that it's religion, tell me it's God, tell me whatever you want. Everything happens for a reason.

[00:00:24]

[00:00:27] **Brittany:** [00:00:27] Welcome to Living Transplant,

[00:00:29] **Courtney:** [00:00:29] the podcast that takes you behind the scenes of the transplant program at Toronto General Hospital

[00:00:34] **Brittany:** [00:00:34] and brings you open and honest conversations about the transplant experience.

[00:00:38] **Courtney:** [00:00:38] My name is Courtney and I'm the communication specialist for the Centre for Living Organ Donation.

[00:00:42] **Brittany:** [00:00:42] And my name is Brittany. I'm a bedside nurse in the Ajmera Transplant Centre.

[00:00:46] **Courtney:** [00:00:46] Full disclosure: we are not physicians.

[00:00:49] **Brittany:** [00:00:49] No. And we are not here to give you medical advice.

[00:00:52] **Courtney:** [00:00:52] Think of us like your guides through the world of transplant, as we know it.

[00:00:55] **Brittany:** [00:00:55] Whether transplant is your past, present or future, your passion or [00:01:00] your curiosity ,

[00:01:01] **Courtney:** [00:01:01] Living Transplant will show you the world of transplant like you've never seen it before.

[00:01:05] **Brittany:** [00:01:05] Welcome back to Living Transplant. Our interview today is with Sonia and Jamie. So Sonia had donated a part of her liver to her father, Jamie.

[00:01:14] **Courtney:** [00:01:14] Yeah, I think back in 2018, we'll get to the details in the, in the interview but what I found really striking about this story is just how close their whole family is.

[00:01:24] Like Sonia is the youngest of three brothers, all four kids applied to be Jamie's donor. And, you know, obviously the youngest and the only girl is the one who's the only

viable candidate. So that part is, is really interesting. And then also just thinking about what Sonia's mother went through, like having a husband and a child going through major surgery, taking care of both of them, post recovery, like working full time. It's just wild.

[00:01:49] **Brittany:** [00:01:49] I know. I don't even understand how some women do it - being able to watch their loved one, go through- things change mentally, physically, and [00:02:00] emotionally must be so draining, but the strength of a woman always perseveres every single time. But being able to watch yourself go through that must be really tough because Jamie talked about how emotional it was for him to go through those changes and his family to even watch it must've been so difficult, and having those emotional changes and physical changes happen being told that you have literal months left to live without a transplant can be daunting. But through this liver transplant, thank God for Sonia. She was able to donate her dad.

[00:02:42] **Courtney:** [00:02:42] Yeah, for sure. Like how rapid things change for their family, is one of the parts that also really amazes me. And that's what I find so scary about liver disease. But despite all that, they talk about everything with such humor like they are so funny. I think so much of this interview is just editing is just like [00:03:00] unintelligible, like laughing and being, trying to talk over each other.

[00:03:03] So they're a great bunch. And even like, encephalopathy it's obviously not funny at all, but the way that they talk about some of his, encephalopathic moments are like, you can't help, but laugh a little bit.

[00:03:16] **Brittany:** [00:03:16] Yeah. They definitely bring light to the situation and the struggles that they went through.

[00:03:21] So let's get to the interview with Sonia and Jamie.

[00:03:27] **Courtney:** [00:03:27] Our guests today are Jamie and Sonia Munoz Thank you both for joining us today.

[00:03:35] **Sonia:** [00:03:35] Yes thanks for having us.

[00:03:36] **Courtney:** [00:03:36] So what is your connections to transplant?

[00:03:39] **Sonia:** [00:03:39] I personally, to be honest, I didn't know the liver regenerated until I had to like go into this situation cause there's no like, advertisement. , I don't know if I missed that day in school when they taught us this, but I don't remember learning about this. I don't remember like having any type of course type of any information or media or [00:04:00] advertising, nothing, nothing. I didn't have any idea until I was put in this situation of like, my dad,

[00:04:05] **Brittany:** [00:04:05] I don't think a lot of people know that, but right about their liver regenerating.

[00:04:09] **Sonia:** [00:04:09] Some people were like, so like, so like you lost your liver, like what happens?

[00:04:11] **Jamie:** [00:04:11] Yeah, that's another part that people, it's really hard to explain that it's only a portion of the liver that is being used and the part that has been taken away, it grows, not 100%, but it's close to a hundred percent

[00:04:22] **Sonia:** [00:04:22] Yeah it's fully functional.

[00:04:25] **Jamie:** [00:04:25] As long we, take the medication because no matter what is that comparable, no matter what is my daughter, genetic it's okay. Everything is okay, but always the body say, no no, this is not mine, get outta here. So that's part of the treatment too, right?

[00:04:39] **Courtney:** [00:04:39] When did you find out that your liver was failing?

[00:04:42] **Jamie:** [00:04:42] That was back to, August, 2017. Yeah. That it was a feeling not really in a good condition. I was getting tired and I was just sleeping in general, I wasn't feeling well, right?

[00:04:57] But it was okay. No big deal, I guess it's the age whatever, [00:05:00] but, September it was getting worse. I started retaining water. So my body started getting a little bit bigger and all this stuff. So I went to the doctor and the doctor said, you know, we're going to do an ultrasound and we're gonna do this and this and this.

[00:05:12] So finally when I got the ultrasound, they, told me and I got cirrhosis. So I was surprised because how'd I get, I get cirrhosis because cirrhosis is always, combined with alcohol and drinking and all the problems. Right. And I was stopping drinking six years previous to that, so it was not related to that. Right. So finally they send me to a specialist - gastrologist? So he say, yep, you have this and you have three months to live. Yeah. One of those doctors that I love it to deal with.

[00:05:50] **Brittany:** [00:05:50] So cut throat just right to the point eh?

[00:05:53] **Jamie:** [00:05:53] The only way you can survive is having a transplant. So we started the process, the paperwork, send it back, do this [00:06:00] one, more tests come back and forward, but at the same time, my ability to walk, it start getting really bad. I was not able to walk properly. I need help. And then by, I think it was October, I was not able to move myself.

[00:06:15] **Sonia:** [00:06:15] And you lost like-

[00:06:16] **Jamie:** [00:06:16] and that started losing weight. A lot of weight.

[00:06:20] **Brittany:** [00:06:20] Was the ability not to walk because of the fluid or because of the fatigue?

[00:06:24] **Jamie:** [00:06:24] The fluid. It was too big. My legs, they were so big my arms, my belly was getting really big.

[00:06:30] **Sonia:** [00:06:30] His, but like it was, it was crazy cause like his belly would get so big, but he was losing so much weight and he was just like, I got to a point where he was so skinny.

[00:06:39] **Brittany:** [00:06:39] Yeah

[00:06:40] **Sonia:** [00:06:40] It was like unrecognized. Like, like James, like my nephew, his grandson didn't recognize him cause he just wasn't the guy that he, you know, grew up knowing. It's even for me, like I've known him for 26 years and he's always been a, he's a tall guy. He's always kinda been a little bit more, not, f- , bigger by any [00:07:00] means. But no, he wasn't skinny.

[00:07:05] **Jamie:** [00:07:05] But at that time I was 250-

[00:07:07] **Sonia:** [00:07:07] - and he was drinking and he was drinking a lot at that time. And like alcohol is, is a big calorie consumer so when he stopped drinking, he lost weight, but he was at an average size. And then after this, he just got so skinny and it was like crazy to see him like that.

[00:07:21] **Jamie:** [00:07:21] For the family, it was really hard to see me because I was not the same person. Even my grandkid, he was like, not really getting close to me. He was like, I don't know you. And just, he was three years [old] at that time. So it was like I don't recognize you. So was he never -

[00:07:36] **Sonia:** [00:07:36] - really, yeah, they were best best friends.

[00:07:39] **Jamie:** [00:07:39] So it was really hard. So also because of the toxins that I was retaining in the fluid, it was getting to my brain. So my brain is not working properly, like totally doing these stupidities and horrible stuff. Like my brain it was somewhere else...

[00:07:54] **Sonia:** [00:07:54] Can I tell the Uber story?

[00:07:55] **Jamie:** [00:07:55] Yeah, sure. Okay. I don't remember those right?

[00:07:59] **Sonia:** [00:07:59] No, I [00:08:00] know. That's fine. I'm not holding you accountable for this. That's fine. Okay, so , it got to that point where he was like, he wasn't thinking straight. It was all the medication, all the drugs, everything. , He really wanted to go out and we're like, you're not allowed to drive. Like you can't be going out. Just to stay home like, well, get whatever you need. Like it's fine.

[00:08:18] So he orders an Uber and the Uber driver is waiting outside and my dad is in like the mental state of like, I'm going like, I have all my clothes on. No, you can't keep me. And I'm like, dad, like, where are you going? Like I'll drive you like, where are you going? And he wouldn't listen to any of us. And this is at the point where he's sick and like he needs a cane to walk, like he shouldn't be going out. Like this is just not good. ,

[00:08:40] So , I'm trying to stop him, my sister in law, Jasmine is trying to stop him and she's a very small, petite little Taiwanese girl , like just super sweet, like would never yell at anyone. And like, my dad is, she's trying to hold my dad back, this tiny girl trying to hold my

dad. And my dad's like, no, no, no, no, no, no. And like they start yelling at [00:09:00] each other and, I call my brother, he needs to come here. He leaves the shop. My brother's a bigger set guy, so he's holding my dad back and we were like, he pays the Uber guy. He's like, I'm sorry. My dad is not like taking any Uber's today. Like this isn't happening. He's not mentally here. He pays the guy, the guy leaves. And then we basically had to cancel - oh my God, the pens! My dad had this thing about pens, so, okay, so the Uber driver got canceled. We kind of like try to cancel his Uber account, try to get rid of his credit cards. He was spending, every single day there'd be a package from Amazon at the doorstep. Every single day. And you know what, he was buying: single pens, just one, just one. But he was buying boxes and boxes cause he -- just like ballpoint pens, any pens because he wanted to give them as gifts to people, as like, thank you for helping us out kind of thing. Like he was like, I gotta get a pen for, Tachita, Donita I gotta get a pen for here here here here. And we're like dad no one even uses pens anymore. Everyone has phones.

[00:09:57] **Jamie:** [00:09:57] It was, I think it was part of the [00:10:00] knowing that I was, that I only have three months at that point, it was two months and I'm going to die. So I just, I guess in part of my brain it was telling me, you know, buy something, so people can remember you. Something like that. Right. So I try to put together all this stuff now, but at that time it was really hard to see it. , So what I understand now is that was part of saying goodbye to everyone right. , because I wasn't able to see the people at that point, and I don't want them to see me too, because it was really hard for them. I have, a couple of friends, they saw me and they were crying, and every time they cry, I feel bad for them not for me. , But they were really hard because, , they were telling me, but you're not the same. You're not the person that we know. You're not Jamie, you're not this and this. And this is, so for me it was hard because it was a big process.

[00:10:46] **Courtney:** [00:10:46] So, they say that you have three months to live and they just, send you home?

[00:10:50] **Jamie:** [00:10:50] I was home at one point, but, one of the days that we came here, all my other three sons and Sonia to be tested, and Daniellia, another friend of [00:11:00] Sonia's, to be tested, who's going to be the best choice. The doctor saw me and she say, no, you cannot go back to your house. You're dying right now.

[00:11:09] **Sonia:** [00:11:09] You were admitted that same day.

[00:11:11] **Jamie:** [00:11:11] I was in intensive care for three days, because my toxins they were too elevated, like, , she would just, she saw me, I was, I don't know how I got a plastic bag and I was sitting waiting outside and somehow she saw me walking and I put up my bag on my head.

[00:11:24] **Brittany:** [00:11:24] Oh boy. ,

[00:11:25] **Jamie:** [00:11:25] And she's, she just immediately just react like a doctor and say something wrong with this person. What's wrong with him? She said something's wrong with your toxins. , So we couldn't do the test

[00:11:36] **Sonia:** [00:11:36] Yeah. So, so we had, so it was my oldest brother, Jamie. Then goes Ricardo, then Victor, then myself, and then my, one of my best friends, also, had opted to do this for my dad. , So sorry.

[00:11:49] **Jamie:** [00:11:49] No, that's okay.

[00:11:50] **Sonia:** [00:11:50] That's - it's just something - that's really close that she would do something like that for my dad. ,Umm. So we all went and my dad was waiting in the doctor's office , and we were [00:12:00] all waiting to kinda go through all the channels of everything. And then , like we didn't get to progress with anything else because he was just too sick and they immediately admitted him in and then we were going to do a different day. But , they managed to do it without us all coming back and the results of like Jamie, Jamie was going through his own thing. He was having like, what does it hurt? Like what was it?

[00:12:22] **Jamie:** [00:12:22] Heart condition.

[00:12:23] **Sonia:** [00:12:23] Heart condition. Yeah.

[00:12:24] **Jamie:** [00:12:24] He was admitted to the hospital with some kind of like, I dunno, it was tachycardia or something like that. , But they say, you're not fit to , do anything. You're not, yeah. You're not going You're not in a good condition right now. Right. Right. So, and then the second one is Ricardo, they told us, after the test, they say no, you have fatty liver, you cannot do this. , And the third one, Victor, they tell him, no, you're too fat. Yeah, you have to lose too much -

[00:12:54] **Sonia:** [00:12:54] you have to lose 40 pounds in a month. Like it was something so ridiculous. It was like, [00:13:00] okay, we can't, we can't go with you. So then there was me.

[00:13:02] **Jamie:** [00:13:02] She was the last one. But it was kind of like a fight between them. Jamie is the oldest one, he wants to do it. 'It's my responsibility' and in the Latino culture, I dunno, all cultures but we have a tradition that the oldest one is always taken care of when , the parents are not there. Right? So they are always going to be, okay, I'm responsible. I'm in charge of you guys, no matter what you're married or whatever, you're responsible still. Right. So he was feeling a responsibility. So , he wants to do it but I guess it was so much stress on him that he,

[00:13:32] **Courtney:** [00:13:32] Yeah. , That's a lot of pressure on you too though, Sonia.

[00:13:35] **Sonia:** [00:13:35] It was a lot . Throughout the whole thing, once they had chosen, it was after my birthday weekend. I know that because they were like, no more alcohol and I was like, great, fantastic. I just celebrated my birthday. I'm cool with that. Like, no fried foods, try not to like injure yourself too much. That whole thing. It was a lot. But at the whole time and the whole process of it, they were always so supportive and like, you don't have to do this. Like, you don't have to go through with this. No one's putting a [00:14:00] gun to you saying like, you need to do this. This is your choice. Like, if you're not comfortable with it, that's okay. No one's going to judge you for it. No one's going to think badly of it and nothing like that.

[00:14:07] **Brittany:** [00:14:07] Yeah, that's a lot of pressure.

[00:14:08] **Sonia:** [00:14:08] It's a lot of pressure, but it's kind of a, it's a choice of like, do I want to see my dad or not? And that's such an easy question.

[00:14:15] **Brittany:** [00:14:15] At the end of the day, like a simple answer. Yeah. Well, yeah, I'm going to do this.

[00:14:19] **Sonia:** [00:14:19] Yes. 100% it's pressure. It's stress, but like at the same time, it's, it's an obvious route I'm going to go.

[00:14:25] **Jamie:** [00:14:25] Also you have to continue your life too, right? Yeah, yeah.

[00:14:28] **Sonia:** [00:14:28] Yeah. And moving forward after that, it was so sped up because what is a usual transplant timeline look like?

[00:14:38] **Courtney:** [00:14:38] I think for liver, it's probably like three to six months.

[00:14:41] **Brittany:** [00:14:41] Right.

[00:14:42] **Sonia:** [00:14:42] We had a month. Like we, everything got fast tracked and it was like throughout the whole process, it was just cirrhosis of the liver. Like we really didn't have a diagnosis of -

[00:14:52] **Jamie:** [00:14:52] NASH, none alcoholic cirrhosis, but after all this stuff, they discovered when they took the liver that I have cancer, I [00:15:00] had a tumor, but no matter what MRI, scan and all this stuff.

[00:15:04] **Brittany:** [00:15:04] No. They figured that out when they were in the transplant.

[00:15:07] **Sonia:** [00:15:07] Yeah. Once they had the liver, once they had my dad's liver and they did a biopsy of it, then they discovered it was, yeah. We had no clue. We had no idea what was going on.

[00:15:15] **Jamie:** [00:15:15] Then there was another worry after the surgery, after the transplant, it was so many more tests a lot of more tests. I learned later that. Part of the problem was caused by my lung, believe it or not, back to what the school teaches. And when you miss that class, they did not explain us in schools that every single organ is connected. What did we learn in school is this is the -

[00:15:39] **Brittany:** [00:15:39] - heart, this is the lungs, -

[00:15:41] **Jamie:** [00:15:41] - this is the stomach, this is the pancreas, this is blah, blah, blah.

[00:15:44] But they don't explain the, how do they connect? How do they work together? I had a bacteria in my lung that was living there for many, many years. It was caused by smoke. I was smoking like 33 years ago and that bacteria was there, but it [00:16:00] wasn't active, it was not ready to work. Somehow something happened in my body that it was activated and when through my lungs to the liver. And it was creating the cancer that they discovered later. So crazy. ,

[00:16:12] **Brittany:** [00:16:12] So you got the biopsy and they said, that's hepatic cancer. Yeah. And then -

[00:16:19] **Jamie:** [00:16:19] - the lung specialist because I have so much fluid in my lung and they say it was after the surgery. So they sent me back after a year. And when the doctors start doing all the tests, he discovered that, he went to back to the doctors here, and they told him, you know what? This NASH that you call it in the beginning, it was caused by the lungs because he had had bacteria in the lung and the lung....they didn't know that too. It was like unbelievable the way it was working. It was just one thing that it caused by smoking.

[00:16:51] **Brittany:** [00:16:51] Wow.

[00:16:52] **Sonia:** [00:16:52] Wow. And that was when you were smoking and you hadn't smoked in like 30 years. 30 40 years ago.

[00:16:56] **Jamie:** [00:16:56] I quit. Yeah, it was, yeah. So that was creating the [00:17:00] problem. So, now they discovered that my chromosome 14 had a deficient. Chromosome 14 is in charge of producing protein in the body, so that chromosome 14 is not producing that protein. That's how the bacteria, got in my lung. It's a long process.

[00:17:15] **Sonia:** [00:17:15] It's crazy. Yeah.

[00:17:18] **Jamie:** [00:17:18] So now my kids have to test -

[00:17:21] **Sonia:** [00:17:21] - to make sure we don't have it. Or if we do have,

[00:17:23] **Jamie:** [00:17:23] - they have it. Right. But they have to see how it can be active again. And that's what they told them. Don't smoke because smoking is the worst thing for that.

[00:17:32] **Brittany:** [00:17:32] They had to test for that, if they had that chromosome and how it would become activated ? This a geneticists that you had to see?

[00:17:38] **Jamie:** [00:17:38] Yeah. Yeah. So my dad and my mom had it, but back to those day, I knew my dad died because of cancer, but my mother, because there was no autopsy, they didn't know.

[00:17:49] **Sonia:** [00:17:49] This is in El Salvador, also.

[00:17:51] **Jamie:** [00:17:51] But now they tell me, no, no, no. In order for you to have that one, your mom or your father have cancer too. Period.

[00:17:58] **Courtney:** [00:17:58] Wow. It's crazy.. that they can trace [00:18:00] things back-

[00:18:00] **Jamie:** [00:18:00] -without any autopsy yeah. I knew my mom died of cancer, not because,

[00:18:05] **Courtney:** [00:18:05] So this is all stuff you find out way, way post, right?

[00:18:09] **Sonia:** [00:18:09] Yeah, yeah. Now, now, like recently.

[00:18:13] **Brittany:** [00:18:13] So it's almost like in a way, your transplant experience and your liver cancer has somehow helped all the people within your family figure out-

[00:18:24] **Jamie:** [00:18:24] -oh yeah. And more people too. Cause I tell the people what happened to me and they say, oh my God, I have somebody that has the same situation or similar situation. So there are like a kind of like awareness. And sometimes we think that smoking is not big deal, but it is, , if you have that deficient , or we don't know -

[00:18:41] **Brittany:** [00:18:41] You wouldn't know.

[00:18:42] **Jamie:** [00:18:42] Thirty years ago, how are you going to know that?

[00:18:44] **Courtney:** [00:18:44] So going back to like chronologically where we were in your story. So you are streamlined for testing.

[00:18:51] **Sonia:** [00:18:51] So we're now in doing everything that you would do three to six months in like a month for the next , seven weeks, eight weeks maybe I was coming in and out of the [00:19:00] hospital doing testing all the time, , getting blood work done all the time. My dad was, you were here the whole time, right? So he was like, after the day he was admitted, like , he wasn't going home , he was there. And so now my mom is taking care of this man, taking care of the household, taking care of my brothers and myself , working her job , on the board of directors for children's aid society. Okay. Volunteering at the church, mom's super woman-ing all of this and like staying here with my dad some nights and sleeping in a chair. Like it was, it was, it was crazy. So. , we're all figuring stuff out at the house. I'm still going to work , house was under construction. Like there was so much that was going on, , Victor and Alana were, were - found out they were pregnant, but like couldn't tell him cause we didn't know what was going to happen the entire time that I'm doing all this testing. My dad has no idea it's me that was chosen. My [00:20:00] dad knew that I was going in for tests, but like no one ever said like, hey, like Sonia is the one, like we're, we're, we're going with her. And some stuff. We didn't tell you -

[00:20:08] **Jamie:** [00:20:08] -a lot of stuff.

[00:20:09] **Brittany:** [00:20:09] Was it because of his confusion?

[00:20:12] **Jamie:** [00:20:12] Because I was under a lot of drugs and because of the drugs. And I told the doctors, right at the beginning when I told them, you know what, I'm - I have an addiction and when you're an addict, you're going to be an addict forever because it's in your brain. It's not in your body, it's in your brain. So , having any kind of drugs in your body, your brain going that react exactly the same, as when you were drinking when you were using, when you were doing whatever you were doing before. So I was reacting exactly the same. If you go to the seven floor and you ask for Jamie Munoz, nobody's going to laugh.

[00:20:43] **Sonia:** [00:20:43] Here and then also at like Oshawa General and when he was in ICU there, for sure, for sure.

[00:20:48] **Brittany:** [00:20:48] Jamie just walks on the floor and they're like,

[00:20:50] **Jamie:** [00:20:50] One day I disappeared and I came here because - I cannot eat any salty food.

[00:20:57] **Sonia:** [00:20:57] Oh yeah. He was on a super [00:21:00] restricted, like fluid. Oh man, you and crushed ice. Aw man.

[00:21:04] **Brittany:** [00:21:04] Because their mouth is really dry.

[00:21:06] **Sonia:** [00:21:06] Yeah.

[00:21:07] **Brittany:** [00:21:07] Super, super dry.

[00:21:08] **Sonia:** [00:21:08] But he was on such a restricted limit for the amount of liquids 500 mils, less. Yeah. Yeah. And my dad is insane when he wasn't mentally there, and it's just like, he's like, no, no, no, no. He's like Chona, Chona, Chona sneak me some ice.

[00:21:23] **Jamie:** [00:21:23] The people that were helping at night, the people that are at doors, I guess somebody hired them just to keep an eye on people. I was bribing them. I'm going to give you a \$20 you can buy whatever you want.

[00:21:41] **Sonia:** [00:21:41] I got offered a car one time. ,I want to make that clear. I never got a car

[00:21:58] **Jamie:** [00:21:58] It was part of the drugs right? [00:22:00] So it was - maybe I can have a conversation with you for five minutes, and then after that I cannot remember, don't even remember people, they, they told me, you know, I went to see you. Don't remember I had no recollection.

[00:22:09] **Sonia:** [00:22:09] No idea. Yeah.

[00:22:10] **Brittany:** [00:22:10] Did they mention anything about encephalopathy? We you encephalopathic?

[00:22:14] **Jamie:** [00:22:14] Yeah. Oh, yeah. Well,

[00:22:15] **Brittany:** [00:22:15] So when you're encephalopathic, toxins in your liver, which one of the toxins that your liver detoxifies is ammonia, and ammonia builds up in your bloodstream, which then causes you to be very confused. It's a term called hepatic encephalopathy. So then they give you this fun drug called lactulose, which is, a laxative, And depending on how bad the liver has failed, , you may be taking it, every two hours, so that you're pooping out the ammonia.

[00:22:45] **Sonia:** [00:22:45] That makes sense.

[00:22:45] **Brittany:** [00:22:45] You're a little bit more awake and for safety reasons.

[00:22:49] **Jamie:** [00:22:49] On top of that, they have to drain me. I had the -

[00:22:51] **Brittany:** [00:22:51] - paracentesis

[00:22:52] **Jamie:** [00:22:52] Paracentesis right. There were like four or five paracentesis and they were painful. One of them, it was, I guess there were new doctors, I [00:23:00] don't know, , but they went through that, they couldn't make it properly. And they pinched, I think it was an artery,

[00:23:06] **Brittany:** [00:23:06] - an artery.

[00:23:07] **Jamie:** [00:23:07] And they discover, but they didn't realize that it was bad until four hours. I was bleeding out of my bed and my wife saw that there was a lot of blood on the floor.

[00:23:17] **Sonia:** [00:23:17] It got scary like it was, this is when you were in Oshawa this was in those early stages. This was before TGH really became your home.

[00:23:26] **Jamie:** [00:23:26] It happened here.

[00:23:27] **Sonia:** [00:23:27] What?

[00:23:27] **Jamie:** [00:23:27] The same problem.

[00:23:28] **Sonia:** [00:23:28] Same problem again ?

[00:23:29] **Brittany:** [00:23:29] Because the liver is, is also responsible for clotting. If you have liver failure, you're not able to clot as easily, so they just bleed bleed bleed, it's very difficult.

[00:23:38] **Jamie:** [00:23:38] You have to be very careful. Every time they have to do the, the, ,scan, they have to do a lot of stuff so they can see where are they going. Some doctor there have so many spirits, they just go like magic. Right. But some can't do it. They have to use with the - the ultrasound - so that was part of the big problem at the beginning.

[00:23:55] **Sonia:** [00:23:55] ,Those days he wasn't even like coherent, like we, my brothers and I would go and see them. My mom would be [00:24:00] there. That's what my mom would sleep there too. I slept there one night. And like he wouldn't really be awake. He wouldn't really talk and it was so hard cause like you never saw this, you know, Victor was crying in the, in the waiting room. Like everyone was getting super emotional cause like we didn't know what was going on and you were just, you went from such good health to like, you're dying.

[00:24:18] **Jamie:** [00:24:18] Yeah.

[00:24:19] **Courtney:** [00:24:19] So , your surgery date was schedule - d do I have this right? - right before Christmas

[00:24:23] **Sonia:** [00:24:23] It was the 21st that was the original surgery date. Yeah. So it was the 21st so throughout the testing throughout everything, everything seemed to be fine. Ultrasounds, breathing tests, CT scans, MRIs, blood tests. Just coming to Toronto all the time. Sorry, I said Toronto really weird. Coming to Toronto. I swear I'm from here. From

Whitby, so we're driving. My mom is driving all the time, we get into the surgery, we get the call, they give us the date, get there. My mom and I stay at an Airbnb.

[00:24:53] **Jamie:** [00:24:53] What happened is, at that day, they canceled the surgery because somebody died, somebody passed away, and they can [00:25:00] use -

[00:25:00] **Sonia:** [00:25:00] They were an organ donor.

[00:25:01] **Jamie:** [00:25:01] It was like four or five different organs.

[00:25:02] **Sonia:** [00:25:02] Like the rooms are occupied for obvious reasons, but -

[00:25:05] **Jamie:** [00:25:05] It was really hard for her. For me, it was like -

[00:25:07] **Sonia:** [00:25:07] yeah, he just found out that morning of, like, for me, I was just like, Oh, , What? I was, I was angry. I was upset. I didn't, but like at the same time, I was like, I get it, you're saving so many lives with this one person. And, I understand it, But I was like, just heartbroken. I was like, yeah, we were so close. We were like right there.

[00:25:21] **Jamie:** [00:25:21] And it was around Christmas,

[00:25:23] **Sonia:** [00:25:23] Christmas. So, , We got, yeah, we snuck him away. I mean, we didn't sneak him out. We asked, the doctors were like, listen to the surgery's not going to happen, can he come home and spend Christmas with like his grandkids and like all of us. So they said, yeah, it was okay. We got him out for a little bit, and then on the 26th they called and said that we had confirmed a date for the 28th and when they told me that it was canceled on the 21st they said, because it's the Christmas season, a lot of doctors are out and like, it's not the full staff, and it might not be till January that you'll see another date. And so they called me on the 26th and like, yeah, so we picked a day, we got the 28th and in my head they told me not till January, so I'm [00:26:00] like, oh man, like another month. They're like, no, no, no, no, two days, like in two days it's happening and I'm like, all right, but like on the phone I was like, listen, like this better happen. Like we're having rooms, like you're putting our names down. Like I'm not going through this again. I'm not putting my dad through this again. Like, no, no, no, cause it, it did upset him.

[00:26:15] **Jamie:** [00:26:15] At one point yes.

[00:26:16] **Sonia:** [00:26:16] Yeah, 100% um -

[00:26:18] **Jamie:** [00:26:18] - I was just tired I was just done because, I was not aware. And no matter what, if they can, I wasn't even aware because there was so much drugs in my body. But it was, so then we got the -

[00:26:28] **Sonia:** [00:26:28] - day. Yeah, the 28th, get there for 5:00 AM, 6:00 AM whatever it is. I was there first cause then you were still in your room cause you didn't go until surgery a little bit later. My surgery was there for 8:00 AM, I waited in the waiting room with my mom, and then you go in and, , you see the doctors, the nurses, the anesthesiologists, you see your coordinators, everyone came by and then my mom was with me. They sent me up., , then they like, roll you away and like you have nothing with you and you say goodbye -

like goodbye. [00:27:00] They roll you in, they put you in a bed., , and then they transferred to another, like, I guess like the surgery table.

[00:27:05] **Courtney:** [00:27:05] Was that scary being rolled away?

[00:27:06] **Sonia:** [00:27:06] Yes. It was like my mom, I was leaving my mom. And like the door is like, it's those double doors. And you know, every, every movie that you see when someone goes through the double doors, it's like, man, so you, so I was in the room. That's literally what happened. So I was in the room and like,, , they're like, okay, like we're going to get you to scoot over to this bed. And so like you scoot over to the other, like the surgery thing and you see the, all the doctors all kind of like, say your names. I don't remember anyone's name, I don't remember anyone's name, but they all introduced themselves to kind of make it a little less scary, I guess.

[00:27:36] **Courtney:** [00:27:36] Did it work?

[00:27:37] **Sonia:** [00:27:37] Well, you know what? You know, we know what happened though, is that the guy, I forgot his name, but he was asking me, oh, like what do you do for a living like this, this, and that, and I was like, oh, like I bartend here and then he's like, all right, I'm going to mix you a cocktail and you're not going to feel a thing. And then you put the mask on me, and then I was gone. So then he went in at 11 and then my mom has like my dad in and then like me in and like this poor [00:28:00] woman, I know.

[00:28:01] **Jamie:** [00:28:01] So for me it was just similar. I just went there and, see a lot of people around, but again, I was under a lot of drugs.

[00:28:09] **Brittany:** [00:28:09] Was this your first surgery as well?

[00:28:11] **Jamie:** [00:28:11] Ah yes.

[00:28:13] **Sonia:** [00:28:13] Yeah.

[00:28:14] **Jamie:** [00:28:14] Like, like that, big? Yes. , I have some other stuff, but it was not like that. It was not -

[00:28:19] **Sonia:** [00:28:19] - a major -

[00:28:19] **Jamie:** [00:28:19] - yeah. And I just remember some guy , telling me, you know, I count to 10 , I just remember I count to 2

[00:28:25] **Brittany:** [00:28:25] Bye!

[00:28:26] **Sonia:** [00:28:26] Yeah, for sure. Right.

[00:28:28] **Jamie:** [00:28:28] Like it was like that.

[00:28:29] And then I started hearing noises. But , maybe a wake up for a minute, I hear noses, but that's it.

[00:28:34] **Sonia:** [00:28:34] And then that was it.

[00:28:35] **Brittany:** [00:28:35] And then what do you remember next? Yeah,

[00:28:36] **Sonia:** [00:28:36] I remember waking up in ICU and , cause they tell you that you're gonna, you might wake up before you get to the actual room, you might wake up when there's still people around, whatever, or you might wake up in the room. I woke up in the room , and , like, your body's just destroyed.

[00:28:51] **Brittany:** [00:28:51] It's hard on the donors.

[00:28:53] **Sonia:** [00:28:53] You're just like, , you can't do anything. Everything hurts. You don't want to eat, you don't want to drink. You don't want nothing. You're just like [00:29:00] roll up in a ball and just, yeah, , I woke up to my brother and his , girlfriend and my mom. , and like, they were there, were there like, you know, you did it, we got this. And we just went and saw dad and dad look so good. Like. , It was crazy. Like, cause you, you started seeing results in like 72 hours. Like your, the yellow in your eyes started to diminish, the yellow in your skin started to get better and you were looking better. And like I remember my brothers saying, we'd go and see dad and dad's doing so much better. And then we'd go and see you and you're just destroyed. And it's just like, it's funny to see the difference. It was hard the first, like two days I feel like I didn't eat, I didn't really do anything. I just laid there kind of thing. And then I, by the third day, I was like, okay, I gotta like get up and like have an appetite going. And I was having booster juices all the time, I think, cause that was just the easiest thing to eat but it was weird having to look down and see like the stitches and all the taping and everything that was there. And just mobility in general. Like once you've lost your core, your back is now [00:30:00] working double time to make up for your core so now your back really hurts and like your core really hurts and you're just, I had, I needed to clean my hair, like I couldn't shower like there was, you weren't allowed to do any of that stuff.

[00:30:10] **Brittany:** [00:30:10] How was that first shower?

[00:30:12] **Sonia:** [00:30:12] It was hard. It was, you know, what it was though, is that I, we had a chair cause like my dad by that time, like we had set up, my brother re-did their whole bathroom and made it accessible, like put bars on the showers, around the, the toilets., had the chairs, had everything. They took the whole bath out, they put it in standing shower, like they made it completely accessible. And so like having a shower in there and like, it was hard. It was, it's hard. It was, I needed help. Like I needed, , my friend, who happens to be a nurse , and , is so gracious and sweet, Ashley , came and helped me with my hair and help braided my hair kind of thing cause I couldn't, put my hands over my head. It did feel really, really good to finally have like a nice, you kinda it like woke you up. It was, it was amazing.

[00:30:57] **Brittany:** [00:30:57] I always tell my patients, I'm like, just wait, wait until you [00:31:00] have that shower. You will feel like a new human. Amazing.

[00:31:02] **Sonia:** [00:31:02] 100% yeah. i'm telling you 100%. It was hard, but it felt really good and it was perfect. It was awesome.

[00:31:09] **Jamie:** [00:31:09] Yeah it was hard cause I just remembered some parts. I don't remember everything. I just remember my son he was beside me, Jamie. And, but my first

reaction was trying to take everything away from me. I didn't - I wasn't conscious of how many cables, cables, wires and every wire, hoses connected to me.

[00:31:31] **Sonia:** [00:31:31] I forgot about all that stuff.

[00:31:32] **Jamie:** [00:31:32] And it was one over here, and they were feeding me through the nose. It was - after two weeks, three weeks, I couldn't see myself. So they show me the picture. See, that was the way you were before. I think I sent it to you.

[00:31:51] **Courtney:** [00:31:51] Oh, I think you did. Yeah. It's a drastic, drastic difference.

[00:31:55] **Brittany:** [00:31:55] I never thought of that, that people don't really know what they look like.

[00:31:58] **Sonia:** [00:31:58] Yeah, [00:32:00] yeah. Oh, for sure.

[00:32:01] **Brittany:** [00:32:01] Just give them a mirror at least.

[00:32:02] **Sonia:** [00:32:02] Yeah, I remember - yeah the neck one was like the worst. I wanted it out immediately. I was like, I don't want this. I was, I'm pretty sure it was fighting with them. I'm like, I want this out now. They're like, no, no, no. You have to wait. I'm like, no, no, no. I want this out now. And then the nose one was was, it was annoying. I had issues with my catheter then no one told me, no offense, no one told me that once they took out the catheter, I needed to pee within a certain amount of hours. I wasn't aware of that, so I didn't go pee and then they came back and then they put one in and I'm like, what do you mean?

[00:32:35] **Courtney:** [00:32:35] Right. So your coloring was like better and stuff you, you weren't feeling better at all?

[00:32:40] **Jamie:** [00:32:40] We just, the problem is, at that point, I learned that my left leg, it was, I can't move it. And they told me that it was part of the risk that when a big surgery like that happened, I might have damaged some nerves? Who knows, but I couldn't move it. So have to, for the next, I think it was three weeks, at the hospital here, [00:33:00] I have to start walking again. Like, because I couldn't move my legs totally. It was dead. So I had to walk, but it was not power. I have no muscles. I have nothing. So it was basically like -

[00:33:13] **Brittany:** [00:33:13] - that's the hard part -

[00:33:14] **Jamie:** [00:33:14] - dead body part, right?

[00:33:15] **Brittany:** [00:33:15] That's the hard part.

[00:33:16] **Jamie:** [00:33:16] Yeah. Start walking a little bit, walking a little bit, but still wasn't mass right. But at one point they say, okay, you know what? We're gonna wait for you until this happened. But meanwhile, we're going to get some, physiotherapy so they can help you with this one. So when they finish that, they transferred to another hospital. To the Grace is supposed to be here for physio, but at one point, after two weeks in the hospital, I said, no, I can't.

[00:33:37] It wasn't working anywhere. I wasn't moving. I wasn't doing anything, I said, I had to get outta here. So I get out of the hospital, I'm going to do it myself. Nobody in my house, there were like 20 steps. I said, I will do it. So they, they, they knew when I say I will do it, I will do it. And, two weeks in the house I learned how to walk again doing all because I was doing, and I feel different, [00:34:00] believe it or not, being in the house.

[00:34:01] It's different. I guess it's home. I don't know. It's part of that touch, that is so close, familiar, everything. So I have to do it. I have to do it. I have to do it every day. It has to do it. I have to move my legs. I had to move it. Finally I got it where my leg is like 95%.

[00:34:21] **Brittany:** [00:34:21] That's a very hard mentality to have, after any type of surgery is, I have to do this. I have to do this. I think a lot of people struggle with that um trying to push themselves and get over that hump, which is the biggest, most important hump to get over determines a lot about your future if you can push yourself. So for sure, for sure. Good for you for doing that. Yeah. I tell all my patients I want you to get up. I always congratulate them because it's a very hard thing to do.

[00:34:52] **Jamie:** [00:34:52] Yeah. So finally I was able to walk and go, I need some help from my kids that were up and down right on the stairs, but it [00:35:00] was just different. It was just a big, huge difference.

[00:35:02] **Sonia:** [00:35:02] What was it like when you, when you drove for the first time?

[00:35:05] **Jamie:** [00:35:05] I was scared. I feel like that was not safe. I was like, like I wasn't like sitting in the middle of nowhere, like, yeah. Yeah. With no protection.

[00:35:15] **Courtney:** [00:35:15] Well after all this like health stuff, it's like we're all so fragile, then yeah, and I'm speeding around in this metal box.

[00:35:22] **Brittany:** [00:35:22] Seatbelt with the scar.

[00:35:24] **Jamie:** [00:35:24] I had to get a pillow, they told me to get a pillow. Yeah. But it was like, if somebody hit me, what's going to happen - so I was real careful

[00:35:33] **Brittany:** [00:35:33] Any little bump...

[00:35:34] **Sonia:** [00:35:34] oh man that was the worst. After the surgery, after the surgery. I think that is the worst, especially Toronto, having so many potholes and so many bumps in the road, it hurts. So much. My dad would like be yelling at my mom - avoid the potholes. My mom's like, there's so many. He's like, you're doing it on purpose, and mom's like, no, [00:36:00] maybe secretly. Maybe a secretly. Oh my God. Yeah. Listen, she needed a win. That was her way.

[00:36:07] **Brittany:** [00:36:07] So Sonia, did you have any complications post?

[00:36:10] **Sonia:** [00:36:10] So after the surgery, getting home and like that, you have to stay on the medication that they give you -

[00:36:17] **Brittany:** [00:36:17] -tinzaparin -

[00:36:17] **Sonia:** [00:36:17] - the needle. The doing that. Like I had a nurse come over the first day and show me how to do it and like where the best place to do it. But it's like, I think it's more of a, it's a mental thing than it is like a physical thing. Like telling yourself you're going to stab yourself with this needle every day and finding new little areas to do it. Like there is, it does tingle. It does sting a little but you get over it. It's just having to tell yourself like, I'm going to poke myself here. I'm going to go here, I'm going to go here. And it's. once you reached that last needle, like at to a point where they give you the boxes, all needles. And like when I knew I was getting towards the end, I would take out all the needles from the box and I put it in a jar and I'm like, Oh, there's only three. And then when I was down to the one I was, that was my last day of the needle. I was so excited. I was like, never [00:37:00] has to do this again. They had given me, what was it. Hydro, hydro, morphine. No, they gave you that. And then before that they had given me like Percosets or like something else to try and the Percocets didn't do anything until I had two. And I'm like, I don't want to create a drug problem here, so can we change it to something else? And then the hydro morphine, I take like one, but at the same time. And I was like, I also don't want to rely on this. Like I want to push myself to, to see what my body is capable of. Cause I came from going to the gym all the time and having a really healthy lifestyle and finally getting to a point in my life where I was like doing really well. And then like surgery happened and just like destroy it all.

[00:37:38] **Brittany:** [00:37:38] Down at the bottom, you're like-

[00:37:39] **Sonia:** [00:37:39] God, it's like climbing back up now with this new challenge of like, like, what am I capable of doing? Is there something I'm going to harm if I do something differently? Or if I twist my body one way, like is it going to affect it somehow? So always asking the doctors, is it okay? What should I be lifting? What should I be doing? How long should I wait before I have weights at the gym? [00:38:00] And like now I think it was almost more of a motivation to like push myself harder than I've ever pushed myself before because it's kind of like I don't have something to prove. It's not that I have something to prove, but it's kind of like you're capable of whatever you put your mind to. It's a whole mind over matter type of thing. And. I'm running faster, I'm lifting more. I'm doing so much more than what I was doing in the gym before. And it's almost like it's focused your attention on something cause it's like, no, you really, really want this. Like you really want to show people it's a normal thing and it, and everyone is capable of doing it. Like it's, it's, it's something that we can all fight and it's a humbling experience. Very humbling. I'd recommend this to anyone. it's just, it's, it's, it's really cool. And it's funny when people say like, you're a hero, you saved your dad's life. And it's like, yeah, but like, it's, it's something that I think anyone should do. Anyone would do. It's, it's not really active heroism. It's, it's so common in like, what is it? Japan has the [00:39:00] highest rate of living organ donors. And it's to their, it's normal. And here it's something that we don't know about. It's something that needs to be spread more.

[00:39:06] **Jamie:** [00:39:06] Absolutely. It's it's a different experience too, right? We're not, I guess as a Canadian, we're not get involved yet in this one because it's new. And -

[00:39:17] **Sonia:** [00:39:17] - they're still learning more and more things about it every time they do a transplant, right. They're learning new things that they didn't know five days ago.

[00:39:24] **Jamie:** [00:39:24] Even having you now here doing this one is new.

[00:39:27] **Sonia:** [00:39:27] Yeah. This whole program of everything, like the newsletter, like getting the newsletter. I was like, Oh, this is so cool. Like you can see all the updates and like, see all the who? is this you? It's great. It's great. No, it's perfect. It's awesome. It gives me everything I need to know.

[00:39:43] **Courtney:** [00:39:43] That's awesome. Yeah. Yeah. I guess we just heard from you what you would like people to know about living organ donation, but Jamie, do you have anything that you would like people to know about maybe someone who's in a similar situation as to the situation you're in before transplant?

[00:39:56] **Jamie:** [00:39:56] I think is the most important is that if you, you're in the hands of the [00:40:00] hospital, the doctors, nurses, and everybody here, you have a hope and part of the hope is just keep waiting, right? Maybe your family, maybe a friend, maybe somebody you don't know might be able to give away that gift and the gift that is for life just forever. Because without that gift it's really hard to be alive, to be alive, but at the same time is to enjoy what is life. All right. Cause I'm enjoying right now with my grandkids, them, I didn't see them at that point. So they just born after the surgery. So I have the the happiness now to see them and enjoy with them. I'm having fun with them, James, that he was the one that he was in doesn't want to deal with me because it wasn't recognize me after. I think it was a year, it would just like, Oh, you were back. You were - the, the gift is just amazing. Right. And to my kids, seeing them growing up, getting married, having kids.

[00:40:55] **Sonia:** [00:40:55] Alana and Victor were pregnant when you were going through the surgery, so they weren't born yet. [00:41:00] And then Catalina wasn't even there. Yeah. Cat is only going to be one in 11 months. Yeah, she's 11 months right now. So like having the opportunity to see your grandkids. If you didn't have this transplant, wouldn't have even been in reality, you would have only seen James. You would have never met Dominic or Catalina.

[00:41:15] **Jamie:** [00:41:15] No. So that day when they told me it was here and I was, I was crying and they said, why are you crying? You should be happy. No, I'm crying because I have the opportunity now to see that right, to be there. Cause I was, when they were born or my fourth kid, I was there. I was assisting them to when they were born. So I want to see them too. I cannot be in the same room, but I want to be there when they come in, out of their room. So it was a beautiful time that I enjoyed. So it is, that's the most important is hope. And it's somebody to keep waiting and praying. Because you don't have to be a religious person, just to wait for a miracle. Miracles are very simple thing. Miracles happened [00:42:00] when something in the middle of the time stop right there. And when that stop happens, tell me that it's religion, tell me it's God, tell me whatever you want. But something happened and that changed everything, everything. Some people they call miracles. Some people, they call it a beautiful surgery.

[00:42:26] **Sonia:** [00:42:26] Doctor's like, we call it a transplant

[00:42:31] **Jamie:** [00:42:31] Everything happens for a reason.

[00:42:32] **Courtney:** [00:42:32] Thank you guys so much for sharing your stories with us.

[00:42:35] **Sonia:** [00:42:35] Absolutely. Absolutely. Thanks for having us.

[00:42:38]

[00:42:38] **Courtney:** [00:42:38] Thanks for listening to this episode of living transplant. If you have questions or suggestions for future episodes, email us@livingorgandonationatuhn.ca.

[00:42:47] **Britt:** [00:42:47] Don't forget to subscribe, rate, and review living transplant on iTunes, Spotify, or wherever you listen to podcasts

[00:42:54] **Courtney:** [00:42:54] and follow us @givelifeUHN on Facebook, Twitter, and Instagram.

[00:42:58] **Brit:** [00:42:58] See you next time.

[00:42:59]