

Claudia Morgan

[00:00:00] [00:00:00] Welcome to living transplant.

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[00:00:03] **Courtney:** [00:00:03] The podcast that takes you behind the scenes of the transplant program at Toronto General Hospital

[00:00:08] **Brittany:** [00:00:08] and brings you open and honest conversations about the transplant experience.

[00:00:12] **Courtney:** [00:00:12] My name is Courtney and I'm the communication specialist for the Centre for Living Organ Donation.

[00:00:17] **Brittany:** [00:00:17] And my name is Brittany. I'm a bedside nurse in the Ajmera Transplant Centre.

[00:00:21] **Courtney:** [00:00:21] Full disclosure: we are not physicians.

[00:00:23] **Brittany:** [00:00:23] No. And we are not here to give you medical advice.

[00:00:26] **Courtney:** [00:00:26] Think of us like your guides through the world of transplant, as we know it.

[00:00:30] **Brittany:** [00:00:30] Whether transplant is your past present or future, your passion or your curiosity,

[00:00:35] **Courtney:** [00:00:35] Living Transplant will show you the world of transplant,

[00:00:38] like you've never seen it before.

[00:00:40] I've heard Claudia's story a few times and I honestly never get tired of hearing it. I think it's the sound of her voice. I mean, you'll, you'll hear later on, but anyway, Claudia Morgan is a floral designer and a living donor kidney transplant recipient.

[00:00:55] So in this interview, Claudia opens up about all sorts of things, her polycystic kidney disease, [00:01:00] running away to Paris when she found out dialysis was in her future, what it's like trying to find a living donor, and her dialysis family.

[00:01:07] **Brittany:** [00:01:07] So this was actually the first interview that we did. And what's really funny about it is that because of scheduling, we had to do this interview at 8:30 in the morning, which means that Courtney was just getting to work, and I was just leaving work after a night shift. So I think the only person that was truly awake in this interview was Claudia.

[00:01:27] **Courtney:** [00:01:27] 100%, which is fine because she does all the talking. So, but yeah, Claudia paints a really holistic picture of what it's like to be diagnosed with polycystic

kidney disease as a teenager, when the prospect of getting a kidney transplant, isn't quite real. And then what it's like to experience kidney failure and how she found her living organ donor,

[00:01:45] **Brittany:** [00:01:45] Um, spoiler alert: this story involves a church group, a viral YouTube video and Japan.

[00:01:52] **Courtney:** [00:01:52] All right, let's get to the interview.

[00:01:58] [00:02:00] **Claudia:** [00:01:59] So I am a recipient of a kidney. I've had my kidney now for 19 months, and, I've been sort of blessed to be, given this new chance at life.

[00:02:12] **Courtney:** [00:02:12] Do you want to start at the beginning? What was your first experience with kidney disease?

[00:02:17] **Claudia:** [00:02:17] Absolutely. So, I come from a family where kidney disease is hereditary. We have polycystic kidney disease that runs in my paternal side of the family. And so from a very early age, I knew that I was going to, at some point need, either a transplant or I was going to go into kidney failure. And so, I was monitored well through my twenties and my thirties, just to make sure that I kept in optimal health for as long as I could.

[00:02:44] **Courtney:** [00:02:44] When did you start showing signs of illness?

[00:02:46] **Claudia:** [00:02:46] Well, they knew I had enlarged kidneys, probably in my teens. but it got progressively worse as I got older.

[00:02:53] **Courtney:** [00:02:53] And did that restrict you at all in your teenage years or was it like life was completely normal and then it all of a sudden [00:03:00] changed? Or were you always being monitored for changes?

[00:03:02] **Claudia:** [00:03:02] I was always monitored, but as a teenager, you know, I did what teenagers do. You just kind of live your life to the fullest and you think you know everything. So yeah, that wasn't really a concern to me at that time. It wasn't until I got into my twenties where I started to get sort of an enlarged abdomen because my kidneys were getting so large that it became more of a health concern for me at that point.

[00:03:24] **Courtney:** [00:03:24] I guess I should have asked this before, but what is polycystic kidney disease? Like what happens?

[00:03:29] **Brittany:** [00:03:29] Yeah, talk, talk us through.

[00:03:30] **Claudia:** [00:03:30] Absolutely. So polycystic kidney disease is basically when the kidneys become sort of infested with fluid filled cysts. And the cysts become so large that they eventually start to deteriorate the function of the kidney. So your, your kidneys should be about the size of your fist. But most patients who have polycystic kidney disease, their kidneys can sometimes be three or four times larger than that.

[00:03:56] **Courtney:** [00:03:56] What's a typical timeline that it would take from being [00:04:00] diagnosed with polycystic kidney disease to needing a transplant or to go on dialysis?

[00:04:05] **Claudia:** [00:04:05] Well, for every patient, it's different. For myself, I had about a 15 year span from the time I was being monitored by a nephrologist to the time that I actually went onto dialysis. But again, it depends on genetics, your diet, how you take care of yourself, all of those are factors that can determine that.

[00:04:23] **Courtney:** [00:04:23] Okay. So around your twenties is when you start showing, or your health starts deteriorating.

[00:04:27] **Claudia:** [00:04:27] That's correct, yeah. . .

[00:04:28] **Courtney:** [00:04:28] And then, so what happens after that?

[00:04:29] **Claudia:** [00:04:29] So after that, I went into my thirties, and I started sort of taking blood pressure medications because one of the key signs of having renal failure is that your blood pressure trust starts to fluctuate quite a bit. So, again, just taking medications. I was constantly monitored by a nephrologist. I would do regular, blood and urine tests to monitor my creatine and those sort of things. And it wasn't until my late thirties that my kidneys really just start to shut down.

[00:04:59] **Courtney:** [00:04:59] Did you [00:05:00] identify as a sick person before then, or like was it, how invasive was the kidney disease before the kidney failure started?

[00:05:07] **Claudia:** [00:05:07] Well, I always say to people, I said, I don't, I didn't realize how sick I was until I started to feel better. I always felt tired. I always felt sick. So I didn't know anything else other than that. So that was my norm.

[00:05:21] **Brittany:** [00:05:21] So you said that this is genetic.

[00:05:23] **Claudia:** [00:05:23] Yes.

[00:05:23] **Brittany:** [00:05:23] Is there anyone else in your family that also had PKD.

[00:05:28] **Claudia:** [00:05:28] So I have a young, I have a younger brother. He does not have PKD. There's sort of like a 50/50 chance, but on my paternal side, my father, my grandmother, my aunts, my uncles, they all have polycystic kidney disease.

[00:05:42] **Brittany:** [00:05:42] And are you the only one to have gotten a transplant?

[00:05:46] **Claudia:** [00:05:46] Yes. I am the only one to date that's had a transplant.

[00:05:49] **Courtney:** [00:05:49] So you're mid thirties you start to get a considerably more unwell, when do they start talking about transplants?

[00:05:57] **Claudia:** [00:05:57] We never had the conversation about transplant until I [00:06:00] started dialysis. So when I got to about 38, 39, my nephrologist started looking at my blood work and saying my creatinine was going higher and higher, and she gave me a

timeline of anywhere between six months to a year before I would actually need to go on dialysis and at that point, you know, thinking the worst, I decided that, okay, you know what, let me just go and enjoy life. I went on a trip to Europe, shortly after I got that diagnosis and I booked myself a trip and I went to Paris, France, and I was there for a little over a week but prior to doing that, I had done some blood and urine samples and I took off. And it's only when I returned back from my vacation that I received 13 missed phone calls from the nephrology team, letting me know that, what should have been six months to a year, didn't even last that long. My kidneys had already dropped down to less than 7%. [00:07:00] So I immediately started dialysis.

[00:07:02] **Courtney:** [00:07:02] Wow. Like you got off the plane -

[00:07:04] **Claudia:** [00:07:04] Oh literally.

[00:07:05] **Courtney:** [00:07:05] Oh my gosh. Yeah. Wow. Wow. And had you had any preconceived ideas about dialysis?

[00:07:12] **Claudia:** [00:07:12] Well, I had seen my father on dialysis, so I, I sort of knew what that entailed. And I had also seen, his brother who had done peritoneal dialysis. So I, I had an idea of what that entailed, but for myself, no. Nobody ever prepares you for something like that.

[00:07:28] **Courtney:** [00:07:28] Right. And, and what was it like your first time on dialysis?

[00:07:31] **Claudia:** [00:07:31] It was a lot rougher than I thought it would be. They walk you through the process, but to actually be hooked up onto a machine and to have your blood sort of taken out and recirculated and filtered back into your body, it's quite daunting. You know, I, I didn't realize how tired I would feel. My blood pressure dropped a little bit low during that first session. But I have to admit that after a couple of sessions, I did start to feel better.

[00:07:56] **Brittany:** [00:07:56] What type of dialysis did you have?

[00:07:58] **Claudia:** [00:07:58] So I did hemodialysis but I [00:08:00] didn't have a fistula. I've never had a fistula. I've always used a line.

[00:08:03] **Courtney:** [00:08:03] And what does that mean? .

[00:08:04] **Brittany:** [00:08:04] Vasc cath?

[00:08:05] **Claudia:** [00:08:05] Yes.

[00:08:06] **Brittany:** [00:08:06] Yes. Okay.

[00:08:07] **Courtney:** [00:08:07] Again, what does that mean?

[00:08:09] **Claudia:** [00:08:09] Okay, so in layman's terms, so a fistula is when they basically connect a vein in the artery in your arm so that it becomes enlarged so that they can use that to put a needle in and take blood from there to go through your dialyzer, which is the machine that filters your blood. If you, if you're not able to do that, whether it's you have

small veins or perhaps it's just not physically possible for you, then what they do is they put a line in, which is something that goes in through your chest and that sort of, it sticks out of your chest and they hook you up through that versus going through your arm.

[00:08:46] **Brittany:** [00:08:46] It's almost like an IV, like what most people understand is an IV, it just goes right into the vein. A vascular catheter is a little bit more of a longer term, more permanent version of what an [00:09:00] IV would be. To analogize it -- I know not a lot of people understand what a pick is or a vast cath is or anything like that for hemo purposes. But yeah, there's many different types of access sites that a hemo patient can use. And you used, the catheter version.

[00:09:16] **Courtney:** [00:09:16] Okay. So. Even after you start to feel better after a few sessions of dialysis, did you ever consider a dialysis as kind of the longterm treatment for PKD or were you like, absolutely not. I need to look into other options.

[00:09:32] **Claudia:** [00:09:32] Well, to be honest with you, I really never thought about transplantation. I didn't know anybody who had ever had a transplant. None of my family members had ever had any sort of transplantation or even considered that. Most of them went on dialysis and they either, passed away at early ages or they just stayed on dialysis for the remainder of their lives.

[00:09:53] So it wasn't until I was on dialysis for several months that my nephrologist came to me and said, you know what, you're quite [00:10:00] young have you ever given any thought to perhaps doing a kidney transplant? And at that point, that's when the doors sort of opened up. And information was given to me about what is transplantation, what does that entail and what are the benefits of doing a transplant.

[00:10:16] **Courtney:** [00:10:16] And was living organ donation brought up to you right away? Was that in that initial transplant conversation?

[00:10:21] **Claudia:** [00:10:21] Absolutely, yes. Yes. Because at that time I was having a lot of difficulty with my, with my catheter, my line. During the course of a year and a half while I was on dialysis, I had eight line changes. Hmm. So the line was not working for me, so I was in sort of dire need of something else, cause I don't know how long I could have stayed on that. So they did mention to me the possibility of looking into getting a live donor and that's where the conversation was sort of opened up about where can one look for getting a live donor, opening that conversation with family members and friends about live donorship. So that's initially what I did. My mom was the first one that stepped forward and [00:11:00] volunteered to get tested to be a possible donor for myself. And during the course of being tested, she found out that she was diabetic, which is something that she didn't know. So in some ways it's a blessing because the testing is so thorough that if there's any sort of health issues that you may not have known about at that time, they're definitely going to come to light during the testing process.

[00:11:24] **Brittany:** [00:11:24] A thousand percent. Yeah.

[00:11:26] **Courtney:** [00:11:26] We get a lot of questions at the Centre all the time about how do you start the conversation. A lot of people are really concerned about the ask. How do you make that ask? How did you go about that?

[00:11:36] **Claudia:** [00:11:36] Well, I often tell people, I say, it's not about the big ask, it's about the big tell. The, the key to it is making sure that you let people know what you're going through. I can honestly say that for myself, a lot of my coworkers, a lot of people that were in my community, didn't even know that I was on dialysis. I was a very private person. I felt in some ways that I didn't want to air my dirty laundry.

[00:12:00] [00:12:00] And so I kept it hidden for quite some time. And it wasn't until I actually opened that conversation to say, "you know what, this is what my life looks like now, I'm reliant on a machine to keep me alive," that people start to sort of understand and say, "okay, well tell me more." And that's how you open that conversation.

[00:12:21] **Courtney:** [00:12:21] And what did that feel like to be so vulnerable and to tell people that you were dependent on a machine?

[00:12:26] **Claudia:** [00:12:26] It's scary at first because you, nobody likes to lay their whole life on the line, but you, you know, you have to understand that you are your biggest advocate. If you don't open that conversation, who will?

[00:12:38] **Brittany:** [00:12:38] Yeah.

[00:12:39] **Claudia:** [00:12:39] Yeah.

[00:12:39] **Brittany:** [00:12:39] Claudia, when you were, first approached by your nephrologist about the option of transplant, were you overwhelmed? Was it like, yeah, "that sounds like a great idea," or was it kind of shocking? How did you take that?

[00:12:52] **Claudia:** [00:12:52] It's kind of shocking because there's a whole bunch of questions that you have that run through your mind. First, where do I start? [00:13:00] Is that, is it getting hurt? What's my life gonna be like afterwards? There's 1,000,001 questions that are running through your mind and you're not even sure where to begin. You're still trying to process the fact that you're on dialysis in the first place, let alone, you know, going and having a conversation with somebody saying can I get a kidney from you? So yeah, it's definitely overwhelming, but I think at some point in time, it just, in my mind, it came in and said, what the, what do I have to lose? You know? Yeah.

[00:13:29] **Courtney:** [00:13:29] Right. So. Okay. Getting back to the timeline, your mom steps forward. She's not a candidate. She's now dealing with the fact that she, has diabetes. Yes. where do you go from here?

[00:13:41] **Claudia:** [00:13:41] So at that point, I didn't have any other options. I just sort of said to myself, that's it. I'm going to just live my life on dialysis. I wasn't going to ask my brother. I didn't know anybody else that I could possibly ask or even if I wanted to ask. So at that point, I went to my church family, which [00:14:00] I'm very close to, and I sat down with my, my pastor and my youth pastor, and I explained to them my frustrations that I was

feeling at that time. I didn't want to really open up to anybody else, but I felt quite comfortable in speaking with them and I let them know that I was feeling frustrated and that I felt like there was really no hope for me.

[00:14:21] And at that point they said, well, what can we do to help you? And I said, well, you know, at this stage, just pray for me. That's all I really need. Just pray for me. I was in such an emotional state that I couldn't even pray for myself, and at that point, my youth pastor said to me, well, you know what? We definitely are going to pray for you, but I think there's something that we can do to help. How do you feel about doing a social media video? Telling your story and letting people know what you're going through and what life was like for you on dialysis. And I thought, I, I don't know how comfortable I feel about that.

[00:14:54] Again, I'm a private person. I don't know if I want to put my business out there. But he said to me, you know what? What do you [00:15:00] have to lose, you know? And he said, well, let's make the video. If you still feel like you don't want to share your story, then we'll never, we'll never post the video. But if you feel comfortable enough, then I think people would love to hear what you're going through and, could really connect by seeing this video. So he came to my workplace, we made this video with me just talking about my life, talking about my trip to Paris and how I came back, finding out that my kidney function had dropped down to 7% and after he finished the video and I saw the, you know, the rough copy of it, he said, well, Claud, are you still feeling the same way about, you know, not sharing your story? And I said, you know what? No, go ahead and post it. You know, I think I'm in a place where, you know, I feel fine sharing it. Go ahead. Little did I know with the way that social media is, is how quickly news can travel.

[00:15:53] And so that video was posted on Facebook and within a couple of hours it had gone viral [00:16:00] and it had been shared multiple, multiple, multiple times till eventually my story ended up going to a missionary that was stationed in Okinawa, Japan.

[00:16:09] **Brittany:** [00:16:09] Wow, I was not expecting you to say that. I thought you're going to say Michigan, but it didn't go there.

[00:16:21] **Claudia:** [00:16:21] It went to Okinawa, Japan, where there was a missionary that from our church, she was stationed there and she saw the video and she said it touched her. Quite tremendously. And she said, she sent me a message saying, you know what? I think I really want to go get tested. But again, there's a language barrier in Japanese on how do you explain kidney transplant, getting tested. There's, there's a whole lot of logistical issues there. So in the process of her going to find out how to get tested. Her sister also saw the video and her sister stepped forward and said, this video really touched my heart and I too think I want to step [00:17:00] forward and get tested to be a potential donor for you. And I didn't think anything of it. I thought, okay, well yeah, sure, they say that. And a couple of weeks later I heard back from the sister of the missionary saying I'm going to do another set of testing.

[00:17:15] And I, and every time I would get an email from her was, we're going for another set of testing or we're going for another and another. Until eventually she said to me, I just

want to let you know that the transplant team says they're not going to search anymore, that we're a perfect match.

[00:17:30] **Brittany:** [00:17:30] Oh my gosh. In Japan, in Japan?!

[00:17:34] **Courtney:** [00:17:34] So no, so the sister's, the sister's, the sister's here.

[00:17:41] **Claudia:** [00:17:41] The kidney isn't coming from Japan. Oh, no, no, no, it was, it wasn't, it wasn't like Skip the Dishes where they sent it to me here. No, no, no, no. The sister is here in Toronto. Well, I saw the video from her sister [00:18:00] that was in Japan. Yes. Oh yeah. So the story went from Toronto to Japan, back to Toronto, so we can clarify that.

[00:18:07] **Brittany:** [00:18:07] Okay. Okay.

[00:18:09] **Claudia:** [00:18:09] Sorry, so that's, that's how that started. So then. Here I am now in Toronto and I'm conversing with someone that I have never met, and they're saying to me, I'm being tested and everything's going smoothly. But of course, I'm not sure if people are aware that when you're doing the testing process, the donor and the recipient aren't tested by the same group of people. You're kept completely separate. So, I'm not aware of how far along she is in her testing. I'm working with my team here at Toronto General and also at Sunnybrook. I'm getting emails, from my donor saying they're not going to look any further. I'm a, I'm a match to you.

[00:18:58] And I'm thinking, wow, [00:19:00] okay. First of all, who gives a kidney to a perfect stranger? Right? So. Now. I said, okay. I think it's time that we meet, because in the back of my mind, I keep thinking she's going to change her mind. She's going to back out. So probably a few, maybe six months prior to our surgery, I had a lunch with Julia and Julia got an opportunity to meet most of my family, and we hit it off instantly.

[00:19:28] It was like we knew each other all our lives. We share very similar personality traits, even though we're not of the same nationality. Our birthdays are days apart. Julia is a tad younger than I am, but we are in all sense of the word like sisters. We just get along so beautifully, and my family adores Julia. She blended in so well. It was like we known each other forever.

[00:19:55] **Brittany:** [00:19:55] Getting chills here.

[00:19:59] **Courtney:** [00:19:59] But, [00:20:00] so sorry, just to go back to like, like you said, who gives a stranger a kidney when you were going to meet Julia, were you at all like, is this person, yeah.

[00:20:09] **Claudia:** [00:20:09] For sure. For sure. In the back of my mind, I keep thinking, oh no, she's going to back out. She's going to meet me, and she's going to say, oh no, I can't do this. But at no point during our conversations did Julia ever waver, she always felt quite committed to wanting to do this. She said, you know what? Your story really touched me and I feel like I can help you and it's something that I want to do.

[00:20:30] **Brittany:** [00:20:30] That is so beautiful.

[00:20:32] **Claudia:** [00:20:32] She's amazing. I love my sister.

[00:20:34] **Brittany:** [00:20:34] Thank you, Julia.

[00:20:35] **Claudia:** [00:20:35] Yeah, right, right. So.

[00:20:37] **Brittany:** [00:20:37] And her sister in Japan.

[00:20:39] **Claudia:** [00:20:39] Yes, exactly. Thank you Valerie in Japan.

[00:20:41] **Courtney:** [00:20:41] Have you met Valerie?

[00:20:42] **Claudia:** [00:20:42] I have my Valerie, yeah.

[00:20:44] **Brittany:** [00:20:44] In Japan?

[00:20:45] **Claudia:** [00:20:45] No, no, no, no. Not in Japan. I haven't been blessed enough to go there yet, but, yeah, I have met Valerie. Yes.

[00:20:50] **Brittany:** [00:20:50] Awesome.

[00:20:51] **Courtney:** [00:20:51] That's awesome. So you meet, it goes really well. And then your surgery, date is already set by the time you meet?

[00:20:58] **Claudia:** [00:20:58] No. So nothing has been set in stone [00:21:00] in terms of a surgery date. It's just initially us meeting each other and getting to know one another. So a couple months pass. I don't hear anything again from the team. And then I get an email again from Julia, which Julia says, I got a letter in the mail and they say they want to book us for surgery. What date works for you? Oh, wow. So.

[00:21:23] **Brittany:** [00:21:23] Like booking a dinner date.

[00:21:24] **Claudia:** [00:21:24] Well, that's it. So you know, it seemed like it came so fast. But we have to realize the timeline is probably about eight months through the initial testing till the time that we get a date. So it's not like it came over like maybe a month or two. It's eight solid months of testing.

[00:21:40] **Courtney:** [00:21:40] And from the point that you are on dialysis, to the point that you get surgery, how long was that?

[00:21:45] **Claudia:** [00:21:45] That's a year and a half. Year and a half. That's a year and a half.

[00:21:48] **Courtney:** [00:21:48] That's actually not bad from what I hear about,

[00:21:50] **Claudia:** [00:21:50] that's not bad at all. That's not bad at all for live donorship I know for people who are waiting for a deceased doner, that the wait list can be anywhere from seven years or more. So it's [00:22:00] booked for May 22nd of 2018. And , there's a whole lot of preparation that's involved in getting ready for a surgery of that magnitude. In case, people aren't aware when you are getting ready for something that major, , you have to go through a process of meeting with the anesthesiologist, meeting with the transplant

team. And there's also a lot of preparation. So I'm making sure that you have a drug program in place to help cover your medications prior to going in and having your surgery, making sure that you have a, a power of attorney. You have a will drawn up. There's a lot of preparation that goes into that. So that's basically what I was doing leading up to the surgery, was just getting ready for that.

[00:22:42] **Courtney:** [00:22:42] And had you had major surgery before?

[00:22:44] **Claudia:** [00:22:44] Never.

[00:22:45] **Courtney:** [00:22:45] Were you scared?

[00:22:46] **Claudia:** [00:22:46] I was scared and excited at the same time, wasn't sure what to expect. Wasn't sure what the pain level would be like, but at the same token, realizing that this surgery could change my life.

[00:22:57] **Courtney:** [00:22:57] Were you tired of being on dialysis at that [00:23:00] point?

[00:23:00] **Claudia:** [00:23:00] I was, but you know, in some ways, I have that kind of personality where I'm a bit of a joker and so a lot of people, they knew that I was sick, but then I, I was sort of lively and bubbly that it never really, there was never that connect to say, well, she, how sick I really was.

[00:23:17] They would see me come in and I would be joking. I mean, I told people all the time I was going to the spa. I would say that. I'll tell them, I'm like, I'm leaving work, I'm going to the spa. They're like, you go to the spa three times a week. Like, seriously? Who has that kind of money? Yeah, go to the spa. For four hours at a time, you know, clean. They're like, this is the most pampered girl I've ever met. Exactly. I lay in a bed, relax. I have a warm blanket wrapped around me. I mean, it's fabulous.

[00:23:53] But, but that's the mindset that I was in because otherwise I don't think I would've been able to cope for a year and a half.

[00:23:58] **Courtney:** [00:23:58] Absolutely. [00:24:00] Yeah. You do what you gotta do for sure. How did surgery go for you guys? Was it, complicated. How did it go?

[00:24:04] **Claudia:** [00:24:04] So Julia went in at eight o'clock in the morning. She had her surgery and I went in I think in around 12, 12 ish, 1230, somewhere around that time. And so, I was fast asleep. I don't remember anything but the nephrology and - the surgeon came out and told my family that the kidney was working right on the table. It worked instantly and then I was moved to step down, which is basically like the recovery area. I was monitored closely for about a day or two before I moved into a regular room, but, I was going to the bathroom on my own, which is something that I hadn't been able to do while I was on dialysis. I went a little bit, but not much. And there was some pain, but you know, there's the magic of the pain pump, and let me tell you, that's a fabulous thing. You know, you press that button and you're just in ecstasy. So yeah, I was feeling fine.

[00:24:55] **Courtney:** [00:24:55] Aside from the magic blue button, could you feel the difference in your kidney? Obviously you're [00:25:00] going to the bathroom by yourself, so the difference in independence was obvious, but could you feel the difference in your body?

[00:25:05] **Claudia:** [00:25:05] I instantly felt my energy level coming back. One of the first things my family said to me is that your color's coming back. Which I didn't understand at that moment, but what I realized was that because I was so sick and I wasn't able to, get rid of all the toxins that were in my body on my own, I had gotten quite dark. And so in the course of being able to use the washroom, I started to lighten quite a bit. And my skin became brighter, you know, my family said, you're glowing. You just look, you look healthier, your eyes look brighter. Wow. Yeah.

[00:25:39] **Brittany:** [00:25:39] And how was your diet after were you able to eat foods that you couldn't eat before?

[00:25:44] **Claudia:** [00:25:44] Okay. Oh yeah. There's no more renal diets, so it's an adjustment for sure. I know my, well, I have to say this, so the night before my surgery, they allow you to eat up until midnight. And so. They, they brought my, my dinner to me and I said to, they [00:26:00] said to me, well, you know, you can really eat whatever you want.

[00:26:02] I have to admit, I'm not encouraging people to do this, but I snuck down to the vending machine and my dinner was Skittles and Cheetos, and it was the best last meal that I had at that particular time. And I thought to myself, you know what? Whatever happens, at least I'm happy. And then after, after I had surgery, my first breakfast after that was orange juice, bacon and eggs and I was still in the mindset of the renal diet that I remember telling, telling the orderly, I think you made a mistake because there's orange juice on my tray.

[00:26:31] **Brittany:** [00:26:31] They all say that. Everyone says that. No, I didn't.

[00:26:36] **Claudia:** [00:26:36] Exactly. And so, you know, it's really a mindset change because you're so used to doing things a particular way. And then when someone says to you, you know what, no, no, no, no. There's no restrictions anymore. Changing that mindset to say, okay, you know what, my life starts over and I can do a lot of the things I couldn't do before. So yeah, I was enjoying life. And the other thing is I come from a Caribbean family, [00:27:00] so I missed eating mangoes. So I took

[00:27:03] **Brittany:** [00:27:03] What are mangoes high in?

[00:27:05] **Claudia:** [00:27:05] The phosphorus and potassium, my God. So I couldn't have, I couldn't have mangoes. So I remember telling my family the first thing I wanted to eat outside of the hospital is I wanted to have mango and well. I come from a large family, so every person brought a mango, so when I left, I left with like 30 mangos. I don't need that many, but thank you.

[00:27:29] **Brittany:** [00:27:29] I would miss that too. I didn't know that actually that mangoes were high in phosphorus, potassium and potassium. Yeah.

[00:27:34] **Courtney:** [00:27:34] Did you visit Julia when you were both in the hospital together?

[00:27:37] **Claudia:** [00:27:37] I wasn't able to go down to see Julia, but my family did go down and check on her. So Julia was in quite a bit of pain. Just because from the donor standpoint, they're taking something from you versus them giving something to me. So. There was a lot more healing that was involved for Julia. But she, from what I understood, she slept most of the time that she was here. [00:28:00] So I didn't see her initially when I was in the hospital, but I did see her afterwards when we got out of the hospital.

[00:28:04] **Courtney:** [00:28:04] And how was it returning home? How long did it take after surgery until you're able to go home? And then what was it like being home?

[00:28:11] **Claudia:** [00:28:11] So typically patients are in usually around three, I think, three or four days. I stayed in for seven days simply because, I had some complications in terms of my wound staying closed, but that was just because I'm of a larger stature and because I'm have a bigger body mass. It took a little bit longer for my incision to close, so I had to get some staples. But other than that, I was out in about seven days

[00:28:37] **Brittany:** [00:28:37] Very fast.

[00:28:38] **Claudia:** [00:28:38] Yeah, yeah, and so the recovery at home was a pretty good, I was walking around a little bit gingerly, because you don't realize how much you use your core for things like sitting up, standing up . You will have to just move really, really carefully because every time you make those movements, it's painful. But that lasted a couple of weeks, and then after that it was fine.

[00:28:58] **Brittany:** [00:28:58] It's the most important thing is moving.

[00:29:00] **Claudia:** [00:29:00] Oh, for sure.

[00:29:00] **Brittany:** [00:29:00] Yeah. Tell my patients all the time. Like I said it, the most important thing, it sounds very simple. It sounds almost kind of annoying cause everybody tells you all the time, but you have to move, you have to get up, you have to walk around.

[00:29:12] **Claudia:** [00:29:12] For sure. I think shortly after your surgery, they have you up and walking around, the next day.

[00:29:16] **Brittany:** [00:29:16] Well, maybe not walking,

[00:29:18] **Claudia:** [00:29:18] but with your walker, you're trying to do a couple of laps around the floor.

[00:29:23] **Courtney:** [00:29:23] What was your experience with the anti rejection medication? I know that can be super tough.

[00:29:28] **Claudia:** [00:29:28] So initially you go through a sort of like a school where you, go in and you have a training session where they teach you about your medications and before you leave the hospital, your nurse makes sure that you know how to properly give

yourself your medications. You're quite aware of what you're going to have to do prior to leaving the hospital.

[00:29:47] But nobody can prepare you for when you go to the transplant pharmacy and they give you your first set of medications. I kid you not. It's like a one of those reusable shopping bags full of medication and you're [00:30:00] thinking to yourself, wow, I have to take all of this. It's, it can seem overwhelming, but you know, as time progresses, , you're taking less and less medication.

[00:30:09] But yeah, I, I caught on quite quickly. I, I don't think I had ever taken that much medication in the beginning of my life. But now it's just become like my new normal.

[00:30:18] **Courtney:** [00:30:18] And physically it didn't make you feel, I know some people have really, a hard time with it, but physically it was okay. It was just like adapting to the routine of taking more.

[00:30:26] **Claudia:** [00:30:26] Exactly. And also too, it's, you know, you realize, "Hey, you know, it's a, it's a small sacrifice for longterm gain." You know, if I want to stay healthy, I have to take my medication, so that's okay. I can pop a few pills.

[00:30:39] **Courtney:** [00:30:39] Earlier you said you didn't realize how sick you were until you got better. Was there something that you did in your recovery where you're like, "wow. I was very ill before."

[00:30:48] **Claudia:** [00:30:48] Oh, for sure. I, I, there were several times where I would go to the grocery store and just the, the actual act of going and picking out groceries and coming home, I'd be exhausted prior to my surgery. I just would take a [00:31:00] nap, you know, , I just didn't have the energy. And then after I had my surgery and I went and I did grocery shopping, I had energy for days. I felt like I wanted to run a marathon, and that's when I, that's when it occurred to me that, wow, I truly was sick because I just, it was like I wanted to do certain things, but I just didn't have the energy to do it.

[00:31:19] **Courtney:** [00:31:19] Right.

[00:31:19] **Brittany:** [00:31:19] So how do you use your social media now versus when you first got your kidney

[00:31:25] **Claudia:** [00:31:25] I wish I could say that I do. I'm not really like social media savvy. So most times on my social media, I will just post updates on how I'm doing. I do have an Instagram page, and I do sometimes post videos on what life is like for me now. But am I on it very often? No, it's maybe once a month or every couple of weeks. but one of the good things about it is that it's amazing the amount of people that you can connect with using social media. Just like I was able to connect with Valerie all the way in Japan. There were a lot of people who are currently [00:32:00] on dialysis or who have had transplants who send me messages saying, I just saw your video, or I just saw your your post. You know, I'm excited. I have my transplant coming up. I'm excited to see what's going to happen for me. So that's been one of the positive things about social media.

[00:32:17] **Courtney:** [00:32:17] For sure. And you do a lot of in person advocacy and mentorship as well.

[00:32:21] **Claudia:** [00:32:21] Absolutely. So that's one thing about me. I'm a chatterbox, so I, you know, I, I love the, the one-on-one with patients. And I think, too, for me it's a little bit easier because I, can, I, I can more closely relate when I'm actually face to face with a patient. So, I do volunteer work with TAP, which is the transplant ambassador program. I'm over at Sunnybrook Hospital and one of the things that I do is I go back to Sunnybrook, which is where I was doing dialysis, and I speak to the patients there and let them know what life looks like after you've had a transplant. Because most of them, when somebody has a transplant, they disappear. Why would you ever come [00:33:00] back to a dialysis center? Sayonara I'm outta here, but I come back and I say, okay, this is what it looks like. This is what my life is like now. And because they remember seeing you there and I was in the bed next to them, they can relate and they feel quite comfortable to ask me questions that they wouldn't necessarily ask to nephrologist.

[00:33:22] **Courtney:** [00:33:22] Do you remember any of those questions?

[00:33:24] **Claudia:** [00:33:24] Absolutely, so things like, you know, is it really painful? ,How much medication do you have to take? Questions is like, how is intimacy after you've had a kidney? Those sorts of things. And I'm one of those people, I tell people I'm an open book. You can ask me anything. I'm not shy. So, you know, if you don't feel comfortable in asking your nephrologist, I'll tell you from my perspective what my life is like. Can I answer your medical questions? No. But I can certainly give you my perspective and sort of relate to what you're going through.

[00:33:57] **Courtney:** [00:33:57] I've heard a lot of people [00:34:00] talking about not wanting to leave their dialysis family, and for a lot of people, dialysis is their social group. Yeah, . did you experience any of that or do you encounter any of that in TAP and what's, something that you tell those people?

[00:34:13] **Claudia:** [00:34:13] Oh, absolutely. So from my standpoint, I can say that, yes, I didn't miss my dialysis family. I mean, you imagine seeing the same group of people, 52 weeks out of the year because you can't miss dialysis. That's your, that's your lifeline. So you see the same people the same time, three times a week. Of course, they become your family. you're going through the same experience that they're going through. So as soon as you don't see somebody, you instantly think what happened to them? You know, where's, where's that person? Because they're you're a new family member. So there is that sort of sense of loss initially because , you no longer need to go to dialysis. You're not seeing these people anymore. but it's exciting because it's like your life starts over again. You're going into a new phase of life. You missed what you had in the [00:35:00] past, but your future is so much brighter.

[00:35:02] **Brittany:** [00:35:02] Your dialysis family, can you just, specify like who that is is that other dialysis patients or like nurses and nephrologists

[00:35:09] **Claudia:** [00:35:09] Okay. So your, your dialysis family is a combination of patients, their caregivers. Also the nurses and the doctors because all of them play an important role in your overall health. The patients help provide moral support for one another. There might be days where you're not mentally feeling prepared for dialysis and there's nothing more supportive than someone saying to you, you know what? It's okay, you got it today. You know, you can do this. You just have to get through four hours. You got this. And also too, from the caregiver standpoint, there are days where we physically as a patient might not be able to physically withstand dialysis. So we rely on our caregivers to help us on those days when we're not feeling so good.

[00:35:51] There were days where my blood pressure was very, very low, during dialysis, and I would have to call my mom and say, you know what, mum? Can you give me a hand just to get into [00:36:00] my apartment or can you give me a hand to get my coat on? So caregivers really do play an important role in that as well. Then the nurses are the ones who are looking after you, so when you're on your dialyzer, they're the ones who instantly notice if there's something wrong or if there's something that needs to be changed because they're the first line of defense when your nephrologist is maybe doing rounds and they're not there. So you depend on them quite heavily. So it's the whole unit that's, that, that makes it together. Yeah.

[00:36:31] **Courtney:** [00:36:31] What's the most common question you get from dialysis patients?

[00:36:34] **Claudia:** [00:36:34] What do you feel like, now that you have your new kidney, do you feel different? Yes. I feel different. I feel more energetic. I feel more alive. The other biggest question is, is does it hurt? And, I, I, in some ways I, I can chalk it up to saying, I guess it's like mothers who give birth. I'm sure the initial birthing pains are, are quite enormous, but you forget it because at the end of the day, you've got something beautiful. So

[00:36:58] **Courtney:** [00:36:58] Does dialysis hurt or does it [00:37:00] just make you tired?

[00:37:01] **Claudia:** [00:37:01] If you have a line, it does not hurt because there's no needle being inserted into you. If you have a fistula, then yes, there would probably be pain because they have to insert a needle into your arm every time you do dialysis.

[00:37:14] **Courtney:** [00:37:14] So it'd be like getting a shot.

[00:37:15] **Claudia:** [00:37:15] Yes.

[00:37:16] **Courtney:** [00:37:16] What is something you want everyone to know about living organ donation?

[00:37:21] **Claudia:** [00:37:21] Well. Really and truly it's the donors that are making the world of difference for patients like myself, because had anybody told me that Julia would have changed my life so dramatically, you know, I would have said, no, you're kidding. But it's, she really has. She's giving me a second chance at life. So donors are so important. And, and sometimes, you know, opening that conversation with your family to say this is what I would like to do. You know, it can open doors that you didn't even think of cause perhaps

some other family members were thinking the same thing and you just never opened that conversation to say, Hey, we both are thinking about being donors [00:38:00] and, and it doesn't just have to be kidney there is all sorts of organ donation, but again, it's that conversation.

[00:38:08] **Brittany:** [00:38:08] Absolutely.

[00:38:09] **Courtney:** [00:38:09] So one last question. You've been to Paris, do you have any travel plans in the future?

[00:38:14] **Claudia:** [00:38:14] Well, I went to Jamaica for my one year anniversary, which was last May. And that was exciting because I hadn't been able to travel in a little while.

[00:38:24] So. You know, I was a little bit nervous cause I didn't know what that would look like, but it was fantastic. You know, I put my medications in my luggage and I headed off and I had a grand old time. So I'm looking forward to traveling a lot more. I think I'll definitely go back to Paris again. This, this time in a better frame of mind and a better, better physical health and, yeah, I'll definitely enjoy this new chapter of my life.

[00:38:49] **Courtney:** [00:38:49] Well, you have to send us a postcard.

[00:38:50] **Claudia:** [00:38:50] Absolutely.

[00:38:51] **Courtney:** [00:38:51] All right. Thanks, Claudia.

[00:38:52] **Claudia:** [00:38:52] Thank you.

[00:38:53] **Brittany:** [00:38:53] Thank you. Thanks for listening to this episode of living [00:39:00] transplant. If you have questions or suggestions for future episodes, email us livingorgandonation@uhn.ca.

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[00:39:17] **Brit:** [00:39:17] See you next time