Living Transplant Season 4 Ep 7

[00:00:00] Living Transplant is a podcast that takes you behind the scenes of the transplant program at Toronto General Hospital, with the goal to educate, inspire, and fuel your passion about transplant. I'm your host, Candice Coghlan. Thanks for joining us for Season 4. In this episode, I sat down with Tara Elizabeth.

who received not one, but two double lung transplants at a young age. She spoke to me about life with cystic fibrosis, what it felt like to take deep breaths, and how transplant gave her the opportunity to walk down the aisle and get married. We were later joined by Dr. Marcelo Seipel, the surgical director for the Ajmera Transplant Center at UHN and UHN ECLS program, among many other accolades, who also performed Tara's first double lung transplant.

He spoke to us about innovations to expand the donor pool and create more viable lungs for transplant with therapies like light based therapy to inactivate hepatitis C virus, a universal blood type, [00:01:00] lung preservation and repair with ex vivo, and what it is like leading and being part of a team who has now celebrated the 3000th lung transplant.

Please enjoy. Welcome back to the Living Transplant Podcast. I am so excited to have our guest Tara here today. Thank you so much for joining us. Thank you for having me. I'm excited. Awesome. Me too. I'm wondering if you can tell our listeners a little bit about yourself. So my name is Tara, um, I am almost 30 years old.

I'll be 30 probably once this comes out and, uh, I have cystic fibrosis, which has led to me undergoing two double lung transplants. Wow. Sarnia, small town. born and raised here other than going away to school in Guelph and living in Toronto off and on while I was sick and recovering from transplants. So you talked a little bit about living with CF.

I'm wondering if you can speak to me a little bit about growing up [00:02:00] with cystic fibrosis and how that affected your day to day. So I was CF, um, in that I was Fairly healthy, like, relatively speaking. So growing up with CF, uh, basically, the way my parents kind of tackled things was, you know, you wake up and you're gonna have to take some meds, do some treatments, and a few other things you have to do in your morning routine compared to your sisters, but otherwise, you know, go live a regular life.

So, uh, I definitely spent, you know, a couple hours a day doing inhaled meds. Um, I have to take enzymes every time I eat. Um, and I was able to play sports growing up. I played soccer. I played volleyball. Come high school time, um, I actually was in band where I played French horn and trumpet. Uh, so for the most part, I was super healthy.

I'd go to clinic in London every three months or sometimes every four months, depending on. You know, how healthy you were at the time and [00:03:00] what infection was happening, but overall, it impacted day to day, but I didn't know any different. So like hindsight, it's kind of like, oh yeah, like I spent a lot of my childhood doing medical stuff, but like in the moment, it didn't seem like, You know, I didn't know any different.

So it was just my routine. Um, like it was annoying, you know, I had to make sure I got home from school and did my treatments before dinner and had to do a treatment three times a day. So you just had to fit it in. So it was like first thing in the morning, usually after school and then like before bed at night and dependent on same thing, the treatment routine, how long it would take, how sick I was, how much I was coughing kind of thing could.

Impact that, but it wasn't until I was 17 or so, um, so I was like the healthiest I'd been in a while in grade 11 and then come grade 12, I just kind of started to get sicker. And I was [00:04:00] doing more medication, we were trying a bunch of different combinations of IV treatment, oxygen overnight, um, even trying to do some, like, diabetic insulin treatment, even though I wasn't diabetic, um, to support my pancreas, just so that I could try and gain some weight.

Um, everything we tried just was not kind of making me any healthier or fixing any of our problems. I was consuming, you know, 2, 000 calories a day in just, um, like weight health shakes and drinks, trying to get calories into me to put weight on, and my lung function was dropping. I went from the London clinic, they sent me off to sick kids in Toronto for a hospital stay, where they ran a bunch of tests.

just because they had access to more research studies and stuff like that. Um, and one of the tests that they conducted was like how many calories you would burn in a day if you were to just lay in bed and be breathing, like doing nothing else. Um, and my like [00:05:00] calorie intake would have had to exceed 4, 000 calories a day for me to maintain my weight.

And that was just laying in bed. So that kind of explained why I wasn't gaining weight. And I, I didn't necessarily have. Any active infection or problem per se

that they could target and fix and say, like, this is why your lungs are not doing well. Um, so it was at that point that transplant was 1st mentioned to me.

So, I was still, I was 7 still times 17 at the time, just before probably just before the end of my grade 12 year. Um, so I went into the hospital the day after prom. In Toronto, um, and we did all these tests and stuff like that. And I had bartered to, I'm not going to miss prom and I have, you know, by the time I have grad.

So, um, but yeah, so we did like kind of intense IV therapy and we did physiotherapy and we did like a bunch of different things while I was [00:06:00] inpatient. Um, it was at that point that I was on oxygen full time, like overnight, um, still not during the day. And then I would have turned 18 that summer. I was discharged from the hospital.

I had improved like a little bit. So it was more. So let's see where things go. And then, um, I went away to the University of Guelph in September and I had my first adult clinic, um, in Toronto at St. Mike's. So I was transferred from London to Toronto just because they kind of knew my health was deteriorating and I was going to need a transplant at some point.

Um. And at that point, I was still kind of in denial. I was like, I'd been mentioned and I didn't even know that it was a treatment option for cystic fibrosis patients. Um, so like kind of when it was mentioned to me, you had like the initial panic of like, I need a transplant. And then I kind of just forgot about it because I made improvement and went back to day to day life.

Um, so when I went to that first clinic appointment in [00:07:00] Toronto as an adult, and it was Dr. Tellis there that I had, and she kind of just looked at me and said, you can't leave this clinic. Like, you are the sickest patient we have right now, and we need to hospitalize you and get you stabilized and. You know, we're going to do the work up for a transplant and I was kind of like, Oh, okay.

Like I'll run back to school and grab like a suitcase I didn't pack for a hospital stay. And she was like, no, no, like, I mean, you cannot leave. Like, so I was hooked up to oxygen full time. At that point, I was exposed to using a bypass machine, um, just to do the breathing for me and kind of help out and cut back on.

The energy I was wasting just trying to breathe and how did you, how did you feel when you know, you're told you're not leaving was, I remember being probably just more frustrated, but also relieved at the same time. Um, because.

Like, it was annoying that, you know, I'm doing all my meds, I'm doing my [00:08:00] treatment, I'm wearing the oxygen overnight, I'm doing what I'm told to do, and like, it's not working.

But at the same time, like, I was also so tired and sick that it was kind of like, okay, yeah, I'm okay to go lay in the hospital for a few weeks, regain some of that energy, and then go back out and tackle life again. So that was the beginning of October, and I wasn't released. I was in for, like, almost a solid two months.

Yeah, I think it was into December that I got it for two and a half months or so. Um, and at that point it was like, Hey, we've got you stabilized. Uh, like you're not deteriorating even further, you know, IV medication wise, we've got that handled. You're on oxygen full time, you know, sleeping on a BiPAP, relaxing, like we're ready to like list you for lungs.

And this is back well over 10 years ago. So you had to live. In the area, if you're on the transplant list and I kind of just stubbornly was like, but it's Christmas, like, what do you mean I have to stay here? And I had been in the hospital for so long and [00:09:00] I came from small town and I was like, Toronto is terrifying.

I don't want to be here. Like big city. It's a big shock. I was just, yeah, like it was culture shock and health shock. And at that point, I still didn't really realize how sick I was. Because your body does adapt and, and you kind of just work with what you got and you, you know, it was a quick deterioration for me.

But at the same time, it was just kind of once you deteriorated, then you just kind of settled in and, and you kind of figure out how to make things work. So I was stubborn enough to be like, Nope, I'm going home for Christmas. Like, see, yeah, I came, did my hospital stay and. Now I'm going home. Like, um, and it was actually being at home that made me kind of realize how sick I was.

Um, because every year my family always throws a big Christmas Eve party. Um, kind of like an open house drop in and all of our family friends drop by, some relatives, stuff like that. And I [00:10:00] like love it. I, Christmas is my favorite and like, I thrive. So, um, it was at the party that year that I just sat on the couch and like, Didn't even want to talk to anybody.

Carrying a conversation was exhausting. Moving back to my parents house. It's a two story home. So going up the stairs even to get to my bedroom was like a freaking workout. And I would just set it up. So like, once I woke up in the

morning, it was like, Hey, what do I need for my room? Cause I'm going downstairs and I'm not going back up until it's bedtime.

So it was definitely, uh, like a, a big, big change. And I had actually met my, um, my now husband, but my, uh, I guess my first serious boyfriend in the fall and winter, about a year before this. So right as I was still kind of healthy. And then within that year, like he just watched me get sicker and sicker and spend more time in hospitals all out of town.

Um, but he stuck around. Um, and I, I like to joke that either he was. [00:11:00] the dumb one of the relationship or, you know, uh, or he's, he's in it for the right reasons. So, uh, and how incredible it is that you, you know, you, you find your person and it doesn't matter when it is right. Then you have this incredible cheerleader the rest of your life.

You don't have to explain anything to either, right? Cause yes, they've just gone through with you. It is nice. They kind of just get it or. They, he, you know, I know my limits of how much to explain and how much not he, he's a bit more squeamish than I am, but we'll just leave it at that. So, you know, I know which procedures that are like, okay, are you sure you want to come with me for this?

Right. Or, you know, I'm, you know, I always joke like. You know, I have very motherly tendencies. So I'm always like, don't worry. I brought a juice box and I brought this. And the nurses are always like, Oh, are you go like you faint? And I'm like, no, no, he will.

And he he's really, he has built up a lot of [00:12:00] tolerance and a lot of, you know, stomach, uh, over the years. So the first, like first transplant, he was there for all of it and wasn't. As exposed, we've been dating a year, but like, you know, he was right in ICU recovery with me afterwards with my parents and my sisters and stuff, but the 2nd transplant at that point, like, we had been together there.

A while, that's math. I'm not going to math, but we've been together a long time. And at that point, we've been living together and it was like, all right, you're number 1. Without realizing it, obviously, in hindsight now, it shifted our relationship into a very patient and caregiver type relationship, which is like, so I'm into psychology and I go to attend therapy and stuff like that, and like, I've realized we've almost kind of done our relationship and bonding and relationship, you know, kind of, uh, steps backwards of we did sort of the end stage life bonding over I'm Well, not bonding over death, but bonding over the illness and [00:13:00] working through it and being a support.

You know, it was almost, well, by the time I got the lungs and got healthy, it's nearly almost 10 years later. That was like, so now you can do a normal relationship. And it's like, so we're going to talk about money and how to do the chores. So then you almost have the relationship down. And Go. Okay. It's like fresh dating and you have the, Oh, like, how do you look at finances or like, what chores do you like to do?

What ones should I do? Or, you know, so it's been, yeah, we've, we've been through the ringer of things and relearning definitely how to, how to date one another from Christmas at your parents house, where you know, you push to, to get out to those lungs coming two months later. Yeah. What was that like, like, how were you managing and, you know, how did you find out that the lungs were ready for you as well?

[00:14:00] Um, yeah, so like I did, I went home, realized that yeah, I was pretty sick. So it's like, okay, we'll let the holidays pass and we'll go back to clinic. Went back to clinic in Toronto and we're like, Hey, we're ready to list. And they're like, well, you've got another infection. So we're going to treat that first.

Cause it's, it's a delicate balance too. being healthy enough to survive surgery and not add any complications per se. And being obviously sick enough to need an organ transplant as your like last resort, um, treatment method. Uh, so it was, yeah, we're going to run some meds. So I was back in Toronto hospital at St.

Mike's there for two weeks. And then we listed for lungs. Um, and listing for lungs was the actual first, first time around listing process, is all kind of a blur for me because we did a lot of the tests and the procedures that you have to have done to see if you qualify while I was an inpatient um, back October November.

So for me it was just a blur of am I doing this test to figure out what medication they're [00:15:00] giving me for IV or am I doing it for listing for lungs? But come the January of 2012, we sat down with like the coordinator and they said, you know, here's how it works. Here's the statistics of transplant and survival rate.

And this is with CF patients, you know, and these are the risks and whatever. And it was kind of, you're listening to it, but at the same time, I'm like, well, this is like just the next step and the next thing to do. So, um, like I am often asked, like, oh, how did you make that decision? And I'm like, It was, you're gonna die, or here's an option, like, there was no, we had exhausted every other option of, you know, medication and studies and trials and, you know, every possible

thing we could do, so, for me, it was like, it was the decision, obviously, but not really, um.

So, and you're given at that point, you're given a huge binder of all of the information you need to know. You can read through it and it's like from [00:16:00] recovery to surgery to how it works. And I was given a beeper, um, at the time as well. So they're much more modern now. Um, but, uh, I was, yeah, sent home with a beeper and they said, you know, you'll get a call.

And we'll let you know, you have long, you just phone and it ended up being 11 days later that we got the call for lungs and I went into surgery. So I didn't even have time to really process or stew or think about. What is surgery going to be like, or what am I worried about? Or what am I not worried about?

Um, I had my first physio session at the hospital and I was like, okay, this is going to suck. Like got to ride this bike. I got to walk on the treadmill and lift weights. So that again, you're doing that to prep for surgery, be in the best shape you can be in build the core muscles. Fortunately, like I still had some.

muscle. I didn't have any fat on me. I was maybe 72 pounds at the time. Um, so I was very, very thin, but I had been in decent shape. [00:17:00] Like I played volleyball in high school on the team. So like I was, you know, and trumpet still in band in grade 12, even so, you know, I was doing some things well, and we got the call.

My dad and I were sitting in our condo in Toronto. We were watching house. And like of all shows, right? And then, um, I was the hospital calling and I was like, Oh my God, we were just there. What do they want now? Like, I'm not going back. Right? And they were just like, Oh, like, is this Tara? I'm like, yeah, what do you want?

Like moody teenager. Yeah. And they're just like, Oh, so we actually have lungs for you. And it was just kind of like. Wait, what? Because when we listed, like, I was told, you know, the wait time is roughly six to nine months. This is January. My birthday is in July. And they said, you know, you probably don't have six months left.

So we're just going to hope that a match of lungs comes up because, or we're going to have to, you know, use more medicine and [00:18:00] technology to kind of get you and bridge you over to that transplant. Um, um, but yeah, so then I, I went into surgery and it was kind of over and done with before I even

had time to think much about it or change my mind or even be worried or scared for the most part.

So I think that first transplant was probably harder on. On my parents, my parents and friends and family who obviously from the third person saw me getting sicker and sicker. So the, so the first transplant, post first transplant, how did you feel after that? Like, how did that change your life? Again, so because I was young and because Well, they said I was in, it feels weird to say I was in great shape, but I was in great shape, relatively speaking, again, going into surgery.

So I was young, I still had my core muscle, like I was able to pull myself up and sit up in bed, like that kind of thing. Um, so I had the breathing tube out, [00:19:00] um, within the first 24 hours, I think it was. Um, I was up. The only part I really remember about that immediate recovery, because of all the drugs they give you, you forget.

But I do remember taking like that first. Breath after the breathing tube came out and it was kind of like I took a breath in of what I was used to breathing and it was like I could keep going and going and going and going and it was like almost 10 of like a normal breath for myself and to fill up and at that point you're immediately out of surgery so you're swollen and you're probably full of just gunk and whatever and Even just at that point, it was already a thousand times better than before.

Like, mom always said I was like, I used to play with the new lungs. And I'd be sitting there kind of like, like, I'm just kind of breathing and playing or whatever. And she's like, are you okay? What is happening? I'm like, it's just kind of fun. I'm like, you get to do this all the time. Like, like the recovery for me, I think I was like, I was in hospital.[00:20:00]

Less than two weeks I think it was and I was like a cold put me in the hospital longer than this like right so and right away I was up and moving and I'm like, this is how easy it's been for you guys all these years. Like, are you kidding me? Like. So, um. What we take for granted, for sure. Right. And a lot of what I was sheltered from, I, I say thankfully, being born with a genetic illness, so I didn't know any different.

Um, so I, like, I think some of the coping and part of the being used to the medical routine and taking medication and going to appointments and stuff, like, all of that was already second nature for me. Mm hmm. But even though

some of the like, you know, swallowing pills was some of those transplant meds are ginormous and some of them smell horrible.

Oh, I know. That's where research needs to go next. When we get Dr. Seipel in here. Exactly. And I have a gelatin flavored, uh, [00:21:00] cherry medication. Exactly. Even the ones that they say are flavored, they're not like real flavor. No. It's not great. No. But every doctor and respirologist who has done one of my broncs has said I have tried it myself and it is disgusting and I am so sorry I have to do this for you.

And I was just like, I appreciate that. Like, these, the team that you get with specialty medicine is invested. Like, I love that. It's a much different level of care. Like my doctors, my pediatric doctor from London, like I invited him to my wedding and he came to my wedding because it was, we were like best friends.

I invited my, um, Respirologist from, uh, TGH and St. Mike's as well, Dr. Shapiro. And long story short, she did not make it. Um, it was the first time in the 10 years I'd known her that she was sick. So when I saw her in clinic next, I brought her her corsage because I was planning to give her a little shout out and because it's kind of like, I was like, that's how I can kind of give back to that.

Like, I'm around [00:22:00] because you advocated for me and you've kept me alive and you've put up with my annoying tendencies as well. So, um, but it was really cool to have them there for that moment, because especially CF specialists, they don't see their patients grow up. Um, it's only been more recent that CF patients are becoming adults and living long enough to like.

You know, keep that population going. So it's kind of weird to think you're part of that history that's being made for the CF population. So bring me back. You mentioned your wedding. Talk to me about your wedding. How did it feel to walk down the aisle and be able to have this incredible monument in your life?

So we had an agreement that was, we're not having our wedding until I'm healthy because I'm going to be dancing at the wedding and I want to enjoy it. And even logistically to, we say logistically, um, but conversations that were had of, you know, if I end up sick or end up back in the hospital, I'm better to [00:23:00] be legally tied to my parents for handling things than I am to be tied to.

A new husband and we were both young, um, like I would have been 23 when we got engaged. So we did have to factor that in with throughout our

relationship of what's the best way to go about, you know, living together or how do we, cause I was on disability and how do you, so there's different things that we had to look into.

Um, and then we got married January, 2020. So two, almost two years after that, a year and a half. Um, and we, you know, there, we, we paid tribute to my donor at the wedding, um, and to just kind of like my doctors and stuff, we had, um, just a single rose placed on a chair in the front row. So the rose represents CF first, the nickname is 65 roses for cystic fibrosis, and then You know, the butterfly and flower, like anything that brings new life kind of thing relates to transplant and it was just, it was kind of nice to like, have that moment and [00:24:00] be like, well, first of all, like, I made it this far and then second to be like, you know, we're like planning for a future and we're like, ready for that and committed and.

It was, yeah, it just, the wedding itself was absolutely perfect. I would not change anything. It was a lot of, I had to have my dress let out so that it fit because I was healthy and put on a good 30, 40 pounds, not even trying, which was wonderful. Like I went from 70 pounds to, I now weigh like 140 pounds.

So it was amazing, uh, from first transplant to now, that's like a decade, 12 years now, almost, so. Um, we kind of, we, my husband and I ended up separating for a little bit just to, um, work through some personal issues and kind of refocus and get our life, not life priorities straight, but just figure out what the heck, how do you handle a regular relationship, how do I handle being healthy.

And even just looking at, like, who we were as individuals 10 [00:25:00] years down the road of, are you the same person? Like, are we going to get along? Are we good together? Because you shift from that patient caregiver to regular spouse. We do couples therapy and I've done individual therapy and he's done therapy.

And like, like now that we have done that, it's kind of, I was like, Oh, like there was a lot of. trauma in our relationship and there was a lot of even like underlying resentment that we both would have had without realizing we had it of, you know, me being envious of him not being sick and being able to go to work and go out with friends and stuff and him being envious of me getting to stay home and to look back and see like how far we've come and what we've gone through.

And, and the work we're doing now to put into our relationship to give it that good foundation, that communication, that just like full acceptance of who each

other is and that we're not the same person we were 10 years ago, but that's a good thing. And this is just like, I mean, this is just my [00:26:00] relationship with him, like I can't imagine the perspective of from my parents or even from my siblings because I'm the oldest of three, um, three girls and I have an older half sister as well.

So, like, and friends who were, uh, like friends with me along the whole ride of that emotional roller coaster of up and down and. You know how they handled things and you have a friend off sitting in a hospital dying waiting for lungs and you're in first year university having a grand old time going to the bar and like I always like if I'm asked like what the biggest thing that CF took for me is I kind of just say like it took my like childish Ways and my, you know, not having to overthink things or plan it or like just being able to be present in the moment and do something, but in how CF kind of took that from me, it's almost like transplant has kind of given that to me.

It's just kind of like, it's wild, but the fact that somebody, you know, again, when, [00:27:00] once they've passed, they don't need their organ and they, I was able to benefit from that. Um, I'm like, uh, uh, here talking and breathing and working and just existing today. Like I wouldn't be here, um, with, uh, research and the doctors, like there's just so many levels of it.

But you know, CF research has come so far in that, like, you know, people born in 93 when I was born, uh, like the life expectancy of a female was 23. Um, and I, I, like I said, I turned 30 this weekend. So, um, like the fact that I'm making it to my 30th birthday is like. Huge. Whereas, like, I used to plan my, like, life will be done by 30.

So, like, in CF years, it's like 30 is the 80. Like, you know, like, it's, it's even that kind of mentality of Having to shift that process now that I've had this transplant and renewed kind of length and experience for life. So transplant has kind of gifted me with the, you know, living in the moment. [00:28:00] I'm wondering if, uh, if you have any last thoughts or advice that you would like to share with people.

I think at the end of the day, like, obviously I push for organ donation. Yeah. Uh, like when, once you've passed. Um, and they're making it now to a point for, well, some organs you can receive and donate while you're living and you still live a normal life. It is, it does give someone like, you're literally giving them a 2nd chance at life because it is an end stage treatment option and it is that renewed.

Ability to, you know, not just exist, but you're actually living and you're surviving and you're, you're thriving and you get to plan for that future and you get to plan for whatever it is that you want to do tomorrow or the next month or the next year, even. And, uh, for anybody listening who hasn't heard of us, uh, say this multiple times, but if you're thinking of registering, you can go to beadonor.

[00:29:00] ca. Um, but that's, of course, not the last step. Talk to your family as well because, um, you know, your family and your friends have the last say, so make sure that they know that you are registered and that you want to become a donor. Um, and if you have questions, you can always reach out to all of the people who are, you know, part of this community, like, like yourself, Tara.

Absolutely. You live in Sarnia, which has an incredible, um, organ donor rate, I believe. I am so proud of them. Yeah, over 50%. So that is our, our provincial average is 33 percent and Sarnia is 51. So that's incredible. Hello, Dr. Seipel. How are you? Hi there. And there he is. So, uh, thank you so much, Dr. Seiple for joining us.

Um, for those listening, uh, Dr. Marcelo Seiple is the surgical director at the Ajmera Transplant Centre at UHN and the surgical director of UHN ECLS program and a professor of [00:30:00] surgery at the University of Toronto. Thank you so much for joining us. It's my pleasure. So I'm wondering if you can tell us a little bit about yourself and what inspired you to go into your line of work and specifically transplant.

Yeah, so, uh, you know, when we are deciding what to do in, in medicine, um, I got very early on attracted to surgery in like the first year of medical school because I really loved anatomy classes, um, was fascinating to me. The second part of surgery, um, is that you make, um, or you make the changes in people's lives very quickly.

So it's, you know, in a matter of a few hours, um, you know, things can change completely. And, you know, I've read so much about, um, the, the lung transplant team and the incredible innovation and work, um, that your team [00:31:00] and, and the team at Ajmera does. So, um, I would love to dive in and ask you some of the questions about all of this amazing research and starting off with some of the light based therapies that are used to.

to inactivate hepatitis C from donor organs and I'm wondering if you can speak to us about that innovation and research that you've worked on. Right, right. So I think going, going, um, a bit back, um, one of the things that really allow us to

do all this, um, Fascinating, um, innovations was the development of the ex vivo lung perfusion system.

Yes. Which, um, started when I was a master's student in the lab here in 2005, six. And, uh, and that created really a platform that subsequently we can use because the organ is in a functional state instead of being on ice. And so. [00:32:00] You can give not only organ evaluation, but you can give active treatments to improve donor organs, which otherwise wouldn't be suitable for transplant.

And you know, the, the light therapy is just one of them we did about a couple of years ago. And one of the, needs for that was, uh, the fact that many donors, um, back in 2017, 18. 19, they tested positive for hepatitis C and that was the beginning of the, uh, drug overdose, uh, epidemics, uh, you know, with that, we would have multiple lungs that were offered from these donors and we had to say, no, we can't use it.

And they are usually young donors. The lungs are totally healthy otherwise, but it would, you would transmit [00:33:00] hepatitis C to the recipient. And, you know, before these new drug treatments, uh, you know, if you get hepatitis C was a pretty bad disease, we couldn't do that. Um, so, so one of the solutions we looked at was, you know, can we eliminate the virus from the donor organ before doing the transplant?

And, and because the, the hepatitis C virus, it doesn't replicate in the lung cells. It replicates only in the liver cells. The virus that was sitting in the lung was just the one that was residual from the blood. Of the donor, right? Okay. Yeah. And so we put the lines on them on the X Fever device and then.

Would use the light therapy, which very quickly would inactivate the virus and after several hours of perfusion, we could see the organ was basically sterilized from the from this virus. And then we went on and did [00:34:00] transplants and, you know, now is, is, uh, you know, transplanting hepatitis C organs is a routine thing.

We don't even think anymore. Wow. Um, the other thing which was pretty important at that time was we were the only ones doing that. And because of that, we had so many access to U. S. donors because the U. S. centers were not transplanting these lungs. So we had a period of about a year that we got so many offers from the United States.

And that was one of the reasons that we had our record. Year of lung transplants in 2019, which was 212. Oh, my goodness. This year, we're probably going to pass that, you know, which is going to be our breaking our own world record. Incredible. Wow. Yeah. And, uh, recently as Mara celebrated the 3000 lung transplant like that.

[00:35:00] Congratulations. That's a, an incredible milestone. And, you know, hearing all of these things that you talk about, we often think, you know, there is. One next step that will support, um, recipients in needing more transplants that, you know, if we, if we do presumed consent or we have more living donors or, or, or, but really when we look at everything, it's, you know, this culmination of all of this amazing work that is contributing to helping us patients.

I'm wondering if you can talk a little bit more about that ex vivo, um, perfusion and, and how has that increased the number of transplantable lungs to get to this place where you're doing these record numbers? Um, the, one of the major advantages of ex vivo and perfusion, uh, and about 30 to 40% of our transplants go through that process now.

Okay. Is that tho those were lines that we would not [00:36:00] otherwise use. Right. Uh, so we basically double the number of transplants we can do, uh, using that technology. And the other thing, which is very important too, is, uh, because when we evaluate the lines, um, on the device. We also get assurance whether the lung is going to work or not, okay?

Okay. Not, not, not assurance for long term, right? Assurance, assurance for the initial phase, which is, again, very important, right? Mm hmm. If the lung doesn't work in the first few days, then patients need to be on ECMO and there's a lot of other risks on that. Um, so we, we, you know, that's the reason why the transplant teams are very conservative in the donor selection because, you know, if something doesn't look so right with the lung and you go ahead and transplant, you may end up having problems, but the ex [00:37:00] vivo takes that doubt away, you kind of test the organ, you know, before going through the transplant.

So I think that's a really, uh, yeah. Amazing, um, uh, opportunity that's what I call, you know, the, the major impact of the phase one of ex vivo. We're now entering the phase two of ex vivo, which you have further impact, which is we're getting to the point where we're giving active treatments to the organs.

So in the organs have donors have blood clots. We give something to remove blood clots. If they have hepatitis C, we'd give something to treat hepatitis C.

You know, if they have, um, uh, inflammation, we can give something for inflammation. And so we're starting to give these specific treatments. And then, you know, I think the phase three.

of ex vivo is going to be when every organ is going to go through ex vivo, even if the organ is already good. Right. [00:38:00] And the major reason we're going to do that is because we're going to give therapies that is going to modify the organ in a way that when you transplant to the recipient, there won't need to be.

a need for heavy immunosuppression. Okay. So organ will have already modifications that will make a local immunosuppression in the organ. And so you won't need to receive You know, drugs. Um, maybe you still need some, but much lower doses. You know, one of the major problems of lung transplant today, as much as rejection is actually the side effects from immunosuppression, right?

It's for sure. You get CMV infection because of the immune system is low. You get other infections. You can get malignancies or the side effects of drugs. All those things are important that we, um, so I, I think that will make a huge impact in [00:39:00] transportation in general. Yeah. Massive. One, one other, one other, uh, project on Next Vivo that we're very excited to, that we published last year is the modification of the blood type in the ORS.

Um, which also, I think will create a much more equal, uh, distribution for patients on the wait list. You know, right now, we, you know, we can't transplant the sickest patient, uh, as the primary criteria because it depends on the blood type, right? So sometimes I have an A donor, but my sickest patient is an O donor, uh, sorry, an O blood type recipient.

Right. I can't transplant that person, right? But now we created this method where you convert the A type donor line to an O type donor line. And so we can trust them to anyone in the least choose basically, who is the sickest 1 or has the most favorable antibody combination [00:40:00] and so on so far. So we hope to start clinical trials on that as well in upcoming months or next year.

you know, in Canada, at least someone dies every two days waiting for an organ. So hearing about all of these advances to make it, um, easier to transplant organs and thinking, you know, that the potential when somebody does register as a donor, that they truly could save up to eight lives, um, with all of this technology to improve the organs that are allocated.

With the ex vivo machine, um, how long can these organs be put on that machine to do these treatments right now? The time span is about 12 to 18 hours. Oh, well, okay We can keep it but we are making significant strides in the lab to be able to do that for longer So there there are you know, one of the reasons if you think about You know, the lung is [00:41:00] kind of alone in that system, right?

One of the problems that over time, you know, if you have a tissue, um, producing some substances because it's alive. But there is no clearance mechanisms, then that those substances start accumulating and can cause injury. So one of the things we've done that has been able to prolong the perfusion time is, for example, adding a dialysis machine to the ex vivo, right?

So then you clear up all the, you know, electrolytes, you keep, you know, lactate and other things that That are produced by the organ. And so we're getting to 36 hours now with that. Um, and I think we'll be able to get to several days, um, in the future. Yeah. Incredible. And that also, you know, extends the, I [00:42:00] guess, the, The viability to then have the best possible candidate to be found for that organ to write instead of potentially having a couple of calls that may not be the right person for it for that organ, which can be absolutely I mean, um, both both using ex vivo and some other research we've done modifying the temperature of organ preservation now lung transplants are.

No longer a big rush when you have a donor lung out of the body used to be like six hours. Wow. Okay. I think, you know, if you look back five years ago, Five, six years ago, lung is out, we all had to rush and start the transplant at one o'clock in the morning. Oh my goodness. And, um, now we are very comfortable, uh, even without ex vivo, uh, with again, modifications in organ [00:43:00] temperature to, um, to wait 12 to 18 hours, you know, after the organ is removed.

But we have cases of 24 hours and even more, you know, it's a, it's a big thing because you know, we never know when the transplant is going to happen and moving people from their communities. It's a big deal from a, you know, not only costs perspective, but all this, you know, social networking and family.

And the other thing is that. You know, it's a more controversial topic. Um, I am a stronger, strong believer that surgeons and anesthesia and transplant teams should be doing transplants when they are well rested. And again, we, we had our lives doing transplants. At night, you know, um, and we can manage [00:44:00] that, you know, uh, but, you know, medical professionals don't have the same regulatory or say don't have the same regulation as pilots, right?

Pilots, you know, they, they work at night. They, they're not going to work in the next 2 or 3 days, right? We work at night and we are seeing patients at 8 o'clock in the morning again. Yeah, that's wild. You know, and vice versa, right? You may be your whole day working and then you're starting a transplant at midnight.

So I, I'm a strong. Proponent that we should be always starting the transplants in the morning. And I think now with this, this new technology, we're able to do that. And I think that will also improve outcomes and like you make a good point to have. You also work in clinic and research lab and then also do surgeries and like, I mean, and it's funny when you say like, Oh, if I do surgery all night, I still [00:45:00] have to do rounds at 8 a.

m. And I'm like, yeah, I was the patient going, where the heck is the doctor? It's 8 a. m. He's supposed to be here for a wrap, like, but as the patient, even you expect that and you don't think about, you think it's a separate team that is standing in the OR doing something and it's a separate team in my ward.

And like you said, you know, You're gonna put, you want your best people rested. You want your nurse that's taking care of stuff to be rested. And yeah, it's, it's like, it's a good point. Um, and also, you know, you need sometimes more support, right? Right. Yeah. So having more people around, you know, having a colleague you can call.

That is just in the OR nearby, you know, all these things can make a difference in, uh, in, in an urgent situation, right? I have, I have an unrelated question to your plan here, but you had mentioned, you know, on ideally your lung transplant surgery is around eight hours. I know my second transplant was 17 and a half hours.

Now second is a whole different [00:46:00] story, but are, do you have like one primary Surgeon that would be that whole 17 hours or do you kind of like tag in tag out or like how does that work because obviously I'm, I'm often dreamland so I don't know who's doing what but like how does that work from your perspective?

Yeah, in most of the cases there will be one living surgeon. And then, and then the fellows, right? So for, for the whole 17 hours is going to be that one surgeon. Yeah. Oh my goodness. So, um, that is ultimately responsible, but it doesn't need to be that way. We, we also have made some, uh, Decisions, uh, for re transplants, second transplants we would do with, with two staff surgeons.

Um, so. It's less thyrosome. So I'm wondering, you know, Tara and I are both recipients and, uh, we have expressed, you know, [00:47:00] what life after transplant is like and how it's such an incredible change for us and more and more when I've talked to Dr. Shaparo and, you know, anybody really on the Ajmera team, the goal is not just to Survive post transplant, but really to think about the quality of life of the patient and what that's going to look like.

Um, so for, for you guys, how do you ensure quality of life for us versus just simply quantity of years with a transplant? I mean, that decision actually a lot of the times starts even before doing the transplant, right? You know, sometimes there is a lot of debate when you have someone that is so sick, right?

And we say, well, maybe we can pull this patient through transplant, but you know, the patient is already on renal failure. It was going to need to be on dialysis [00:48:00] after. And so then that decision starts at that point. And it's sometimes a difficult one, right? And, um, I think for, for the other patients that come in, in better conditions, uh, of course our goal is.

Is to provide both, um, quality of life and long, long life, right? And, and ultimately we want the organs to outlive the patient. Which is something like when I sat down with you, I think it was when I first went into rejection. Um, which was 22 months. So like, you're kind of not all clear, but you're more clear at two years out with lungs.

Like you're not monitored as closely. Your meds don't change. And I was so close. And it was like, okay, I'm in rejection, like, when do we relist, kind of thing. And then I was like, do we relist? Is this a thing? Like, And it was a lot of, we have treatment options, and then even once we tried all of the available ones at that time, it was, okay, well, we [00:49:00] still want to get as many years out of these lungs as we can for as the patient, I was like, never considered that.

Like for me, it was just, what's the next treatment option? What's the next step? What do I do? Because like, so I waited another two years after doing a year and a half of treatments before we listed. And it was one of those, we know it's going to be a harder match. We know it's going to be a longer wait.

We'll get you on the list while you're in good shape and you can wait versus, you know, My stubborn first time around of, I'm good. I'll wait. And then luckily, you know, got lungs quick, but. And Dr. Seifel, I'll, I'll ask you to, um, you know, when I speak to surgeons specifically as well, often you don't get to see your patients.

Um, most often you don't get to see your patients post transplant, you know, once they leave the hospital and off they go on their lives. And you know, what is it like to be able to. You know, sit in front of Tara. Yeah, no, it's, it's, uh, I mean, it's pretty amazing. I mean, you [00:50:00] know, the, the most common place I see my patients.

Yes. And that's where I first met you. My dad goes, that's your surgeon and it's like awestruck, like the celebrity and it's so common. And sometimes you don't recognize the person, you know, because I see them so sick. Get the transplant done. They, when they leave the ICU, we, we see them maybe once or twice on the ward, but it's mostly the Respirology team.

Yeah. And then, uh, and then we see them maybe three months later in the hospital, you know, and they look so different. You know, and it's, uh, it's amazing. The feeling is really very, as I mentioned, very rewarding. Now we have one more minute with you left, uh, Dr. Seipel. I'm wondering if there's anything that I didn't ask you about that you want to share with our listeners.

Well, um, I think [00:51:00] maybe one important thing to mention is that the patients are, are major, uh, play a major role in our successes as well, and it always, um, strike me how willing they are, um, to make, to make progress in the field. And I, I, you know, I've been part of many of the very innovative research that we've done that if I was a patient, I was going to think, you know, should I really go and accept this?

Right. And he had to tell me no to studies that I wanted to sign up for retransplant. He's like, I don't think it would be best for you. I'm like, no, I'll do it. I'll do it. And the patients tell me, you know. Okay, if it doesn't work for me, yeah, I know that is going to help someone else right in the [00:52:00] future, right?

Uh, it's, it's amazing, uh, the courage and, um, and, you know, the willingness to, to help and support the field. Well, thank you so much, Dr. Seiple, for joining us today and for all of the incredible research and innovation and hard work that you do for, for patients and families and donors. And we're so grateful for all that you and your team do in, in creating better lives for us.

Thank you. Yeah. And thank you so much, Tara, for joining us today and sharing your incredible journey. And as Dr. Seiple said, your, your courage and your bravery, and it's so incredible to get to see you so healthy and enjoying time with. It's nice. It's good. It's good. We're, we're, um, we're actually in the process of figuring out a family planning and, um, Dr.

Shapiro has kind of given us a green light to attempt, um, a pregnancy with med, different med changes and stuff. So it's a process still, and [00:53:00] we're figuring it out what's going to be safest, but it's, uh, if it ends up being a pregnancy or surrogacy or whatever, but again, something you wouldn't have possible from the get go of.

Which is very cool and like it's cool to get to see your surgeons after too and hear their perspective on stuff like, 'cause like you said, you're in the elevator and I'm like, that guy is the cool one. like amazing hands in there. Yeah. So amazing. Well, thank you so much both of you. Good to see you. Yeah, we really appreciate it.

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