Living Transplant Season 4 Ep 10

[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 Cotlin. Thanks for joining us for season four. In this episode, we're celebrating Living Donation Week.

I was joined by Sylvie Charbonneau, past president of the Kidney Foundation of Canada, advocate, and donor. It's a change maker and a living kidney donor to her son. We were also joined by Dr. Joseph Ham, Director of the Kidney Transplant Program at the Ajmera Transplant Center. We discussed barriers and changes that need to be made to increase access to organ donation as a whole across Canada, and how we can support others to receive and give the gift of life.

The passion for supporting the over 3, 500 Canadians waiting for an organ transplant and the hard work that is put in every day made me believe that there is great hope for the future. Please enjoy. Welcome back to the Living Transplant Podcast. I am so grateful to have [00:01:00] Sylvie with me today. Thank you so much for joining me.

Thanks for inviting me. I'm wondering if you can tell our listeners a little bit about yourself. So my name is Sylvie Charbonneau. I'm from, uh, the province of Quebec. I live in a small town, town called Austin, very small, uh, 1800, uh, people. And, uh, I'm the mother of two. I'm the grandmother of two. I've been married for 46 years, believe it or not.

Amazing. Yeah, and, and I became a consultant and I, for almost 30 years, I worked, um, in what we call today change management and organizational transformation. So I was helping and implementing new systems, new processes. Um, I'm now retired, but for about maybe now 10 years, I've been involved a lot with the Kidney Foundation of Canada.

Since we discovered that our son had a kidney [00:02:00] disease, then I joined the board for the Quebec branch. And, uh, I, after that I was nominated the, um, president of national board, um, for three years and now I'm past president. So I've also been involved at the federal level in some working committees. And, uh, I'm the new director for Canadian Transplants Association for the province of Quebec.

So, that's what I do. Amazing. My goodness. And, uh, I'm going to say in air quotes that you said you're retired, but it doesn't really sound like that with all of the volunteering that you do as well. Well, for some people, retirement means you stop. For me, retirement meant that I would move on to do something else.

Um, that I would not be paid for, but, uh, I would help in the best way I could, maybe changing some pieces of the world, uh, in my own little [00:03:00] capacity. So, uh, that's what I call retirement. It's not stopping. It's doing something different, helping in different ways. That's beautiful. And speaking of that change and, uh, the kidney world that you were, uh, thrust into, I'm wondering if you can speak a little bit about your family's journey with kidney disease and that pathway.

Sure. So, um, my husband and I have always said we've been very lucky in life because we have Two great kids. They're not kids anymore. They're always kids to mom. Yeah, 38 and 41. So, but, um, they were very healthy. They were into sports. Both of them were great swimmers when they were younger. And, um, at one point in time when my son, our son, was in university, he had an episode of high blood pressure.

It was just like once, uh, he was practicing a sport, his friend has had to drive him to the hospital because he was not really feeling [00:04:00] well. He was maybe 23 at the time, 22, 23. And they didn't know what happened, but, uh, the doctor said, maybe you should have your kidney checked because you're, Uh, I don't like what I'm seeing in your blood and your, your blood pressure as well.

So, you know, when you're 22, 23, you think you're invincible. So a few years passed and, um, one night he was not feeling well. He was 27 at the time, went to the emergency and, uh, they kept him, did more tests and discovered that his kidney function was only at 25%. So, yeah, so he came, uh, he, he came home one night and he said, well, I don't have very good news.

I have health issues where my kidneys, uh, my kidney function is declining. And, uh, at one point in time I'll have to go through dialysis or I'll need a kidney transplant. Now I'm on a very severe diet. And I don't know if you've seen [00:05:00] the diet of someone who's on dialysis. It's crazy. I think he had five pages of restrictions, but his nephrologist told him you will probably be able to go on for about five years, but his kidney function declined way faster than that.

And after two years on that severe diet, his kidney function was below 15. And so that's when I said, um, because before that, You don't get tested for, um, if, if you want to be a potential donor, but I, I, you know, in the early stages, I told, uh, uh, I told my son, I want to be a donor. If I can do that, I will do it.

So let me know what has to be done. And so I started the process of being evaluated. Uh, of course, the first one is compatibility. I was compatible. Luckily I went through all the tests. Um, I think I was not an easy patient. I was very pushy because I thought that the process was way too slow, too [00:06:00] long. And I was seeing my son declining at the same time, his heart declining.

So, um, I was calling the hospital every other week. What's the next test? Do we have the results? What, what can I do? And finally, after about almost a year of testing, uh, I got accepted as a donor. And, uh, in December of 2012, uh, I was able to give our son, uh, a kidney, I was going to say a new kidney. It was not new, but, but, uh, yeah, I was able to give him a, uh, a new kidney.

Unfortunately, um, during the pandemic, he developed antibodies and rejected my kidney. So that was in. 2021. Uh, he had to go on dialysis for about seven months. He was what we call highly sensitized. He's, he had a lot, a lot of antibodies. And because of that, he was on the, on the top of the priority list across Canada.[00:07:00]

His nephrologist told him you'll probably have to go through at least five years of treatment. Dialysis, because you're highly sensitized and my God, a miracle happened. And in January of 2022, he got a call, a young man, 28 years old died in the Toronto area. The parents accepted to donate his organs and he was a match to, uh, Benoit.

So Benoit received a new kidney in 2022. Yeah. So he, the second transplant was a bit tougher. He was older, he had been on dialysis, uh, he was fighting a virus, but now, you know, touching wood, it's been almost a year and a half and he's doing very well now. So as a, as a mom, you know, my, my mom was my donor.

And, uh, when you were saying that, you know, you were calling and you were maybe not the easiest donor or patient you said, but, you know, knowing how it feels [00:08:00] to be a mom, to have your kid in this situation, no matter what age they are, that really drives you. And, and my mom. said to me, like, it didn't matter what she had to do.

She was going to do it to be the donor. And I'm wondering if you can talk to me about what that's like being a mom and, you know, going through that process. You know, my mom used to say, no matter how old you are, you will always be my kids. And I feel the same way. I think when you have kids, um, You would do anything for them to be well, to be happy.

Uh, and, um, I felt like, you know, if I can help in any way, shape or form, I will do that. You know, sometimes people ask me, how long did it take you to take that decision to donate? And I go like, maybe three seconds. It was as easy as that. I mean, if I, I would even say that if I could have switched places with him and go on [00:09:00] dialysis instead of him, I would have done it, you know, because when you see someone, you love, um, having issues, suffering, getting weaker and weaker.

Um, I mean, when we got the operation, when he got the first transplant in the end, he was so thin. Uh, I mean, I think his weight was, you know, He's six one. I'm five four. His weight was probably the same as mine when I saw him at the hospital, you know, I thought, my God, he's thin. It's, it's incredible. And he likes sports.

He likes good food and seeing him miserable every time he had something in his plate, seeing him also being anxious and he thought every time he would have something to eat. That I or him did not prepare. He was anxiously, he would have anxiety crisis because at one point in time, that's one thing I didn't mention, but at one point in time, his potassium level was so high that his doctor called him and he [00:10:00] said, you get to the emergency right now.

And we're going to call you. Put you on a, um, on a lot of, uh, medication. And if that doesn't work, we're going to start dialysis because you're at risk of having a heart attack. I mean, you're 28, 29. You're not supposed to hear that. You're not supposed to think I may die because of what I have in my plate every night.

That doesn't make sense. You know, kidney diseases, you know, are silent diseases. People around you don't see that you're sick. They just see that you lose weight, that you're a bit tired. They ask. Benoit didn't want to talk about it. He didn't want to get pity from everybody, anybody. And so with, um, him going through this process, what was that impact like on, on your family when, um, Benoit was diagnosed and, you know, you're waiting to see if you were a match for him.

I realized at one point in time that even though I said, I want to donate [00:11:00] and I'll do anything I can to help. There was one point where my husband said he would be tested and our daughter said, I, if it doesn't work with you and dad, I'll go for and be tested myself. And my first reaction when my daughter said that I said, no, you're not going to go.

And she said, mom, if it's good for you, it's good for me. And, um, I, my answer to her was, I cannot picture myself having my two kids on, um, a surgery table at the same time. And what saying that I realized that that was what I was imposing on my daughter and my husband. And so after that moment, um, it made me realize that it's not a story between a donor and a recipient.

It's a family story because everybody's impacted. Of course, as a donor, you go through a surgery, so you have risk like any other surgery, but at the same time, you have to be very healthy to be a donor. [00:12:00] So, um, your risks are quite low. But you're imposing that on, on your family, everybody in the family was suffering for him.

Um, and at the same time, we didn't want to show pity. He didn't want that. But um, every time he would call me or send me a text and say, can you call me? My heart would stop and go, Oh my God, something happened. And it was the same thing for my husband and our daughter. So it's really. It's not just between two people.

It's your close circle. It's also those people who are close to you that are impacted by that and and thinking of that community as we think about the bigger and bigger, you know, scope of this, um, You went through this process and donated to your son and learned so much through this. And then you took all of that lived experience and that passion and, you know, put it into that [00:13:00] transplant community in that kidney community.

I'm wondering if you can talk to us a little bit about first your work with the kidney foundation and how you really got involved there. When I was still going through my, my tests, uh, to become a donor, I asked the hospital there, what can I do to help? Um, because I, I discovered, honestly, I didn't know a lot about, uh, kidney disease, right?

I knew what kidneys were for to a certain extent. I discovered a whole new world, a whole new community, and I, I wanted to help because I discovered that. A lot of people were going through the same thing as my son, and I guess I'm, I'm that type, if I can help, I will raise my hand. So, I just have some, Ask the hospital, the nurse there at the transplant clinic, if I want to get involved and help, what can I do?

Where can I knock? And she said, well, there is the hospital foundation, but there's also the kidney foundation. [00:14:00] So I knocked on the door of the kidney foundation. Actually, a friend of mine brought me there. And, uh, I began by being, um, a volunteer to pre to organize the Montreal walk at that time, it was quite a big walk.

We had almost 500 walkers and I met great people, great volunteers. And I went on, I did a few walks, and then someone approached me and said, Would you like to serve on the board? And I said, Yes. Maybe that's the right place for me to be if I want to change things because coming back from a background in organizational transformation and change management.

My ultimate goal was to help improve the system so that people would go through the process I went through. In an easier way. And when I got this offer to join the board, I said, well, maybe that's the right place to be. Um, when I was the president of the Quebec branch, [00:15:00] I was able to meet with, uh, politicians telling them about my story, telling them about the difficulties navigating through the system, the health system, telling them the impact on donors and recipients and the cost on society, because.

We know today's, you know, uh, studies are showing that the best treatment so far, because there's still no cure for kidney disease, but the best treatment is a living donor. And we're not doing that well. If we compare, well, if we look at, if we look at Quebec and if we look at Canada as a whole, we're not doing that well.

And I always say there's A lot of kidneys walking on those streets and there's all these people waiting for a kidney. Why can't we? Why can't they meet? Um, I know that it's not as simple as that, but still there has to be some ways to improve. So that's why I joined the board. And then when I was Approach to join the national board and became the president.

I thought that maybe I [00:16:00] could influence at a greater level. And because of that, I joined some committees with the ODTC, the organ donation and transplantation collaborative. I met so many great people, but my biggest surprise was to see how many organizations across our country are involved in transplants.

Um, um, organ donation and transplantation. I think the first meeting I attended, there were people from 38 different organizations and I thought, Whoa, this is a very complicated system. Yeah. And so, yeah, you know, things take time, changes take time, but my hope is still to be able to influence in my own way, people who are making decisions in that area, so that at one point in time, we'll be able to simplify, um, the The process for those who are, um, or wishes to those who are wishing to give, uh, give an organ.

It's amazing change to think about, um, [00:17:00] you know, from the, the change that you made in your son's life and your family's life, and then bringing that to a community level. It's incredible that, that you've done all of this. And, you know, I think. When I hear you speak the, the message in my brain is always, you know, you can, you can start somewhere like change.

You don't have to think about the, the massive barriers and all of the complications, you know, you can start small and work up and, you know, make those steps. And like you said, the. The wait times are long across Canada and the, um, you know, the registered donors, uh, you know, I, I think in Ontario right now, we're only at about 35 percent of potential registered organ donors who have registered.

And I think about a third of our transplants that we do at UHN, maybe a little bit more are living donors, but like you said, The best possible treatment for kidney disease is a living donor kidney [00:18:00] transplant. And we can't do that if we don't know more about the process or if the process is so arduous that it's hard for somebody to do it.

And you know, when I was still in that process of being evaluated, one thing I didn't mention was when I got approved. As a donor, I had a meeting with a committee. The committee was taking the decision. There were seven people in the room. I thought I was meeting the surgeon, but when I got in the room and I saw all these people, I thought, Oh, okay, that's not the same story.

But, uh, at the end of that meeting, they said, we're accepting you as a donor. And that was August of, uh, 2012. And they said, you should be able to donate before Christmas. And I just went like, What? It's not next week. I mean, and that's a very stressful period. And I know that people in the health system are doing their best, but if you think about it from the patient's perspective, [00:19:00] you've been accepted.

But you don't know when it's going to happen. And after that, you don't want to get sick. Um, I mean, you know, we, we went through September, October, November, and early December before we got to the surgery room. So, uh, I stormed. Snow. You don't want to fall. You don't want to break anything. You don't want to get sick.

So, you know, my son and I were caught with calling each other two or three times a week. Are you feeling okay? Because we knew that we would get the call and one of us would be sick. It would be postponed. The, the, uh, the surgery would be postponed. And, um, during that time, I don't know how many times I told my husband, I don't have any suicidal thoughts.

But if I would die tonight, but no, I would get my kidney overnight. So I don't, or, you know, in a few days this week. So I don't understand why it's not happening because I'm healthy [00:20:00] and alive. That doesn't make sense to me. And that's, that's probably when I thought. The process has to be improved. We have to find new ways to go through that.

And that's why I'm happy to be involved at the provincial and national level, because I think one of the things we need to look at is yes. You know, I get it. The health system is complicated. We're missing staff, etc. But it's just that the way we think about it, we think about it from the hospital, from the transplant center perspective, not from the patient's perspective so much.

And if I think if we start analyzing those situation from the patient perspective, we'll be more creative. And we'll find more innovative ways to do it waiting and not knowing it's torture. It is. It is awful to make someone wait. And it's [00:21:00] not a way to live. It's a way to survive, but it's not a way to live.

When we were in that period of waiting to get a date for the transplant to happen, uh, the neurosurgeon at one point in time said. You know, your function, your, your kidney function is still deteriorating. So if you don't get that transplant by the end of December, in January, we'll have to start you on dialysis.

And so I was pushing and pushing. I think at that time I was calling the hospital every week, but if you think it, and I don't like to talk that way, but if you think it. Think about it from a global perspective, from a systematic perspective, sending someone on dialysis, someone who has a donor and having that, that pair wait for, you know, weeks and months.

There [00:22:00] are some ripple effects. The first one is the recipient might have to go on dialysis. It's a cost. It's more difficult on the patient's health. First. Secondly, um, some tests that Benoit had and that I had, the more you wait, the more you have to redo those tests because there's an expiry dates on tests.

So you're taking your, Adding cost to the system and you're taking the place of someone who needs those tests that is sick and, um, so to me, that doesn't make sense. Um, you know, we know that the best treatment is a transplant. So why do we wait so long? Why can't we prioritize those surgery and avoid dialysis as much as possible?

I think I'm going to fight till the end on that. Yeah. Because to me, this is a nonsense and no criticism on the staff. I know that the [00:23:00] staff is doing the best they can, but decisions decision makers have to realize that they have a potential here to improve the health of people. And the financial situation of the health system, they have to take that opportunity.

And 1 thing that I, I believe people do not consider enough is that when you prioritize or, um, reduce the wait time for a pair of living donor and recipient. You're also helping somebody else because someone on the waiting list may not have that luck that chance to have a living donor. And if you go through that surgery, you're taking someone out of the list and you're giving the chance of someone who doesn't have a donor to be prioritized.

I mean, it's a win, win, win situation. So, um, Yeah, I strongly believe that we have to push for that. And, uh, you know, every time I have a chance to talk about this to do a [00:24:00] testimonial conference on that, I will always say yes, because I strongly believe that we need no more awareness, we need more visibility for the cause.

And we need to make sure that decisions make decision makers. Have all the information to change the system. I'm wondering if, um, you know, while we're talking about change, if you can, You talked a little bit about the ODTC. I'm wondering if you can chat about some of those things that you've been working on with that group and, you know, thinking about that high level change, what an incredible group of people who are part of that.

I don't know who had the idea, but I think it was such a great idea, such a great initiative to put everybody together across the country. No, uh, provincial or territorial boundaries, sharing ideas, sharing situation. One thing I really, really appreciate there was to have the patient's voice heard and a few [00:25:00] things that are happening.

Uh, I was on a subcommittee for, uh, data and systems, and, uh, we're now developing, uh, acquiring a system to share data across the country, which I Great improvement. When I was still working as a consultant and working with my clients, I used to tell them, you can not, you can not. Improve if you do not measure, and if you do, you cannot know if you're good if you do not compare yourself and having a system across the country, gathering key performance indicators, sharing that with all the centers.

I think will be a great push and a great motivation for all the centers to share the way they do things and to make improvements. It also puts a little pressure on the system, which to me is not a bad thing. Another example that I'm really, really happy that we did is I [00:26:00] was on the living donation working group, and during the pandemic.

We, you know, the, the, the living donors who, um, for the pair exchange, as an example, you may be giving your organ to someone in another province before the pandemic, you had the patient, the donor had to travel to the province of the recipient during the pandemic in some of the meetings, people were asking.

Why can't we just have the organ travel instead of the patient? That's what we're doing now. So this is a great improvement because some people didn't want to travel. It's time consuming. It's costly. And, but, um, now I think we're going to have, uh, more potential living donors. We have a couple minutes before, um, Dr.

Kim joins us and we're going to continue to talk about those big ideas because I think it's, it's so important to, to hear from all aspects, but you know, [00:27:00] there's still a lot of work ahead of us in this field, but I'm on a smaller level. I'm wondering, what do you think from your experience in all of these different aspects?

What do you think we could do to make the journey better for the next family who's coming after us? I think we have, there's a few things. The first one is, I think we have to create more awareness amongst the population. And what I mean by that is, um, I don't know how many times when I was delivering a speech on living donation and the seeds donation that I was telling people, you have to talk to your family and people would say, why I signed my consent.

Yeah, but that's not enough. So, you know, there are all kinds of little things like that. That people don't know that, um, reduces the number of available organs. Second one is, we have to also create [00:28:00] awareness around the impact. On the donor, whenever I tell my story to an audience, the first, their first two questions are, what was the impact on your health?

And do you have a special diet? Do you take any medication? And so, so, and my answers are always the same. Um, I was in pretty good shape. So, you know, four weeks after the surgery, I was back in the office. I was slower, but, uh, I, I didn't have as much energy, but, but still, I was 56. I was not a young kid. And for most people, it's, it will be three months, but for me, it was like, uh, three or four weeks.

Um, I have no special diet. I take no medication. And I feel that today I'm healthier. That I was before because health is a gift and you have to take care of it. So it's a long answer to say, I think one of the things we can [00:29:00] do is awareness awareness amongst the population, uh, awareness amongst the families, the potential donors, um, you know, peer to peer exchange and support for the potential recipient, the potential donors and advocacy for the decision makers so that they can Influence and make it a better and quicker process.

I think today and the way the system works, you just have to push for yourself and people sometimes feel uncomfortable doing that at one point in time. You know, if the pressure doesn't come from the top, the pressure has to come from the bottom. And at one point in time, the pressure will be so strong that something will have to change.

I love that. Wow. That's amazing. I don't know if it's the right way, but that's my way. I think it, I think it'll work. Now, speaking of, uh, some of that pressure from the top, we're going to have, uh, Dr. Joe Kim join us here. So welcome. So, uh, welcome. And thank you so much for [00:30:00] joining us, Dr. Kim. Uh, Dr. Joseph Kim is the director of the kidney transplant program at the Ajmera Transplant Center.

The vice chair of medical advisory committee, associate professor of medicine at the University of Toronto and our wonderful guests today. Thank you so much for joining us. Thanks for having me. It's a pleasure to be here. I'm wondering if you can, uh, tell our listeners a little bit about yourself. Sure.

Um, uh, as you mentioned, uh, my day job is the director of the kidney transplant program at the University Health Network, uh, in the Edgeman Transplant Center. And the kidney transplant program here at the Edgeman Transplant Center is the largest program in Canada. Um, I'm also a, uh, researcher as well. So I have a background, a doctorate in epidemiology and a master's in statistics.

Uh, and I've been in, in this sort of business for, uh, For a long time. So hopefully, uh, I can be helpful in terms of, uh, some of the discussion points today, but also here to learn as much as I am to, uh, to speak to those things. So, yeah, thanks for having me. Amazing. Thank you. [00:31:00] So tell us a little bit about, a little bit more about yourself.

What made you decide to go into nephrology and why specifically transplant? Ah, great question. Yeah. So I can tell you exactly when I decided. So for nephrology, my first year of medical school was the first lecture on, on kidney physiology. I mean, lecture was a very dear colleague who actually is a well known to living donation circles, Dr.

Bob Richardson, who was a former director of our living kidney donation program here at UHSN. And what impressed me the most was how it, Not only did what it did, but it was so important in so many different aspects of of human bodies functioning, and so it's such an important. So not many people know, especially those who don't think about kidneys all the time.

Is that turns out the kidneys are really important in bone health. Who knew that, right? And also very important in making sure that your hemoglobin is in a good range. So the blood system and the bone system and somehow the kidney is a central part of that. So that kind of really stimulated me to [00:32:00] think about kidney health and disease as an area that I'd like to pursue long term.

So, you know, Sylvie and I have talked about our experiences through this, you know, this kidney journey. And, um, for myself, I, I lived on dialysis for about 15 months. Um, I did both hemo and, uh, peritoneal, and now I've had my kidney for, I'll be celebrating 15 years in September, um, which is amazing. Thank you.

Yeah. To think about, um, and I can talk about the differences. You know, personally about dialysis and transplant, but I'm wondering from like a physical perspective in a medical perspective, if you can talk about the difference in in life expectancy and quality of life for us patients who are looking at all of these modalities.

Yeah, it's an important question. And so I'll say this. I mean, dialysis is an incredibly important treatment, and it's evolved tremendously over the last several decades to now [00:33:00] provide a very much a viable treatment. treatment offer option for patients with kidney disease and kidney failure. And part of it is due to the advancements in the technology that allows us to allow blood to be safely circulated through what's called an extracorporeal circuit.

So something outside of the body, because anytime you bring blood outside the body and put it into a circuit, you know, there are, Things that can happen. One of them being, for example, clotting of the blood and so forth. And so, uh, there are now sort of safer ways to deal with that. So, at the end of the day, dialysis now has become a very good treatment option for people with kidney failure, but when compared head to head with getting a kidney transplant, it still does not do quite as well in terms of both life expectancy and quality of life.

So, uh, you'd ask, uh, Candice about sort of the comparison between the two. We did a study actually through, at, uh, we looked at the outcomes of patients who were on a home hemodialysis. We consider one of the best forms of dialysis treatment because you do it at [00:34:00] home, you do it frequently. Mm-Hmm. . And so therefore you start to mimic almost, uh, the kind of, um, kidney function that you would get with a, with almost a, a reasonable kidney.

And so, you know, the question did come up, you know, does a patient on home hemodialysis start to rival both, uh, the benefits that you receive with a kidney transplant? And lo and. kidney transplant still is considerably better. And so if you want to talk about life expectancy, expectancy, I don't have the latest statistics for dialysis per se, but for a kidney transplant, um, you know, we have patients, uh, who with a particular, with a living donor transplant have survived, you know, 30, 40 years with a functioning kidney.

I mean, that, that, that is not inconceivable. And, you know, If you look across a hundred people with a kidney transplant from a living donor on average, about half of them will still have a functioning kidney and doing very well at about 18 to 20 years or so, at least in our program. But remember, don't focus on the 18 to 20 years.

What that means is that 50 percent of people continue to [00:35:00] have function beyond that. And, and, and remember kidney function doesn't mean the kidney itself. It also means, you know, there's other things that unfortunately could impact kidney function in particular. The host being, unfortunately, you know, succumbing to some illness and so forth.

And so the kidney might be working fine, but it's just that, you know, they develop heart disease or other problems as well, which is actually an important area or emphasis as well as that for patients with a kidney, living with kidney transplant and kidney patients in general, an important emphasis on the things that actually can cause your health to deteriorate above and beyond the kidney is a really, really important piece that we can't forget.

And so. Think of the kidney transplant event as a new chapter in your life to sort of try to get rid of all the old vices. Of course, it doesn't always happen that way, but to get rid of the old vices to, You know, implement a regular exercise regimen to eat smart. You can cheat, of course, like anyone else could, but you know, at the same time, on average, always try to be as smart as you can about your diet, exercise regularly, and [00:36:00] try to choose the healthiest lifestyle possible.

But at the end of the day, that's a major part of being able to get the most out of that kidney transplant. So when we talk about transplant, there's different types of transplants, the preemptive transplant. So before dialysis, and then of course, what I did was a living donor transplant and what Sylvie did living donor transplants and deceased donor transplants.

We don't talk a lot about. preemptive transplants. And I know there's been a push in the last, I don't know, five to 10 years to really talk more about that and to bring that education to patients and families and even family doctors. And, and we've seen a lot of the work that BC transplant has done in increasing their preemptive transplants.

I'm wondering if you can talk a little bit about that education and, and you know, the, the new enact trial that started about four years ago in Ontario. And, and what the benefits are of preemptive and, and how we encourage that more. [00:37:00] Yeah. So maybe, uh, let me go back a little bit just to make sure that our listeners are clear about the difference between deceased and living donation and then speak to more to preemptive there.

So, uh, kidney, where kidneys come from are primarily two sources. Number one, the traditional source or the long source that we've sort of long known about, which is. People who, who, uh, are about to pass away who've been identified as a potential donor, someone who will donate their organs for the benefit of others.

Living donation, on the other hand, uh, specifically, uh, is in the realm of kidney and liver transplants because of course with kidney, we're born with two and we can actually, if you're otherwise healthy, live very well with one. But there is a rigorous process by which people are selected to be able to donate because one is that the chance of them staying healthy in the long term is very, very high.

And in general, I think, uh, you know, the, there's a number of advantages if you want to say it that way, uh, of a living donor in the sense that, you know, a few of them would be, of course, that, uh, someone who otherwise would be waiting for deceased donor. So, [00:38:00] again, there is some waiting involved because, you know, not enough kidneys are available.

And so, uh, and usually the biggest factor there is how long you've been on dialysis. But if you have a potential living donor who's been medically cured and compatible with you, then, you know, it turns out you don't have to wait. We can get you booked. And if as long as your medical cleared as well as the recipient candidate, we can then move forward with the operation and get that done in a much more timely way.

The other thing is that by definition, the kidney is coming from someone who's extraordinarily healthy because they've been rigorously medically evaluated. And so these kidneys are, you know, for lack of a better term, they're quite fresh and healthy. And so sometimes kidneys are a little sluggish when you put them in from a deceased donor because it's been through a lot, but usually it starts to pick up over time.

But these kidneys from living donors tend to work right away. Also, just generally, there's, these kidneys do have a greater lifespan because, again, they're from very healthy, uh, the donors. But the other advantage that it provides, especially in our current situation where there's not enough kidney strength to go around, on either front, [00:39:00] is that it gives the opportunity to someone to get a transplant before they need to go on dialysis.

So, so unfortunately, the reality is that deceased donating does not occur preemptively, in the sense that preemptive, meaning before you need dialysis, there is a waiting time for it, and typically that waiting time stands long after starting dialysis. So in reality, we can't do preemptive deceased donor transfer, as we call it, although theoretically it's possible if enough kidneys are available.

However, preemptive So, um, I think, uh, you know, Just kidney transplant as we practice it in most parts of the world is really a living domain. So, as you just mentioned, Candace, you know, there's, there's a trial. The neck trial that was, uh, Conducted in Ontario to try to. Figure out ways to build in supports and other resources for patients to try to promote living donation.

Uh, that the crowd. They completed in. And the results are being put together right now. So we're. I'm not sure. What it goes. But I think. I think [00:40:00] the concept of it is very, very important. If you can avoid dialysis, uh, it, it, it saves the recipient candidates, certainly the, the potential, not only aggravation, but the, you know, complications of having to put in some, uh, a lot, for example, a line or something to access their blood circulation to allow hemodialysis to occur or a catheter in their belly to allow peritoneal dialysis.

That's a procedure in its own right. Also, you tend to feel better when you get that transplant because you're now, you're not quite needing dialysis and then your kidney function, uh, returns substantially as a result of that living. So there's no doubt that if you can do it, a preemptive transplant is the way to go.

But like I said, it unfortunately realistically is tethered to living donating. And so that's the challenge. Okay. And I might be a little controversial here, but this is a conversation. So I want to make sure we put out there that, you know, because it's linked to living donation, we have to transplantation also is linked to kind of having that resource available, having a social network that will allow us To support you to [00:41:00] do that and not it's not equal in our in society.

It's not equal, uh, with respect to, uh, that particular important resource. And so, you know, for example, newly landed immigrants or people of different ethnicities who don't have extent as extensive networks, also certain religious groups and others that have certain beliefs about donate. Unfortunately, does put.

Some individuals behind the eight ball in terms of even being able to consider preemptive transplant. And we, you know, Sylvie has talked a lot about some of the different initiatives that, um, the ODTC have, have worked on and, you know, some of the kidney foundations work and some of the differences and the variations between workups, um, for recipients and donors across Canada.

And I'm, I'm wondering, you know, what it would look like if we And try to standardize these referral processes. And if it would be possible, that might be, you know, the bigger question if, uh, if we could do that. And, uh, you know, [00:42:00] thinking about one day donor workup, um, I'm wondering if you could talk a little bit about what that would look like if we ever could standardize these referral workups.

Now, uh, you've raised a number of important points. So the issue around, uh, standardization or trying to Improve the way we do things around the donation and work up, especially for living donors and support to credit get things moving forward and make sure that patients are getting every opportunity to move towards transplant.

I would strongly agree with the importance of doing that. There is still quite a some variation across practices and across centers and even jurisdictions of this area. The most compelling way to reduce variation is to clearly documented and to understand what the contributors are. And as well as to infuse evidence to try to reduce unwarranted variation wherever it occurs.

And so, uh, those are just some of the key pieces. And I must say, in Canada, we haven't sort of [00:43:00] reached a point where we can really do that in a systematic way, but we're moving that way. So the ODTCs work, for example, one of the key groups that are really sort of undertaking a lot of work to try to improve this space is the data group.

And so I actually co chair that group. Myself, and so we're looking to try to develop, uh, reimagine the data system that captures information about donating transplant across the country, which will give us an opportunity to really understand why practices vary if they do, and how can we minimize those unwarranted.

So notice I said unwarranted. There's always going to be some variation that's appropriate, given the sort of the specific patient, the donor that we need to address. The other piece is around, you know, having a discussion or what the best evidence is and where we should be applying it in ways that helps us begin to reduce that barrier further.

And part of that also requires that the key stakeholders come together, right, and have that conversation. And so in Ontario, we're lucky that we have a strong group in Trillium Gift of Life Network and the committees underlying it to help us start to move that forward. [00:44:00] Forward and we've made efforts to do so and actually there is various working groups right now working on this very issue and and so we're trying to improve that as much as we can, but a lot of times the positive data and the lack of evidence that prevents us being able to come up with some real sort of rigorous standards that we can all agree on your last point around the one day workup is an interesting one.

I think from the perspective and Sylvia could probably speak to this from the perspective of a living donor candidate. It would make life a lot easier if we can sort of cluster all the necessary testing into a relatively short period of time so they can book off that time and get it done. I think ideally, yes, we should try to minimize the number of visits and try to, uh, finish the necessary work up as quickly as possible for living with anxiety.

However, one thing to keep in mind is that usually the rate limiting step in terms of the transplant is not the living donor. It's the recipient candidate, right? A lot of times recipient candidates are medically complex, and so they have to undergo a much more extensive workup and it takes longer. And so the living donor is usually not the [00:45:00] rate limiting step.

In terms of timing, so that that's the piece. So we need to we're focusing on trying to understand how better we can sort of address the medically using concerns of receiving candidates. But certainly from the living during candidates. I think trying to bring all that testing as sort of tightly as possible from a timeline perspective makes a lot of sense.

So what would you say in that, uh, even though you have potential donors, you know, I get it that it's, it's potentially the recipient that is more difficult to evaluate. But if one thing I don't understand, and that's one thing I didn't mention, Candace, is that the fact that we wait for so long when you have a potential donor that we wait until the kidney function is at 15%, let's say.

To start the evaluation of potential donor in the in doing that. there are more chances that the potential recipient will have to go on dialysis. If we start evaluating potential donors earlier, [00:46:00] I think that's one of the objectives of the BC project, transplant first, they, I think they're starting at 25 percent instead of 50%, then you Reduce the chances of, um, needing dialysis.

And, and the last thing, and I know I'm not going to be politically correct here. I'm very sorry for that. I know it's my colors. But, um, and I think, I know that in some areas we have We don't want to go to the private sector for help. I'm going to talk about my personal experience, and I know it's only one case, but in Quebec, when I got evaluated, there was an 18 month waiting list to get a colonoscopy.

I went to the private sector. It took 10 days, and it cost me 500. If I would have waited for 18 months, Benoit would have been on dialysis for probably a year. If you compare the cost of a year of dialysis versus 500 for the test on the in the private [00:47:00] sector. I mean, I rest my case. So, you know, there are things like that.

I think we need to think outside of the box to improve all that evaluation process. Yeah, no, no, all great points. So maybe the last point you raise around sort of, uh, having access to Procedures and other things in a more timely way to allow you to move to work up forward. Absolutely. I mean, unfortunately, that's a province wide issue with respect to these waiting times.

And I think 18 months is unacceptable. I agree with you 100%. Having said that, even, you know, the whole debate around private and public health, that's a separate debate altogether. So I'm not going to, I'm not going to delve into that for another. Exactly. But your point is well taken, Sylvie, and especially from your perspective, it made a lot of sense for you to have that.

Option and that was for in the best interest of yourself and your and your recipient. So absolutely makes a lot of sense in that regard in terms of, uh, you know, working up donors earlier. It does make sense. It does make sense. And, and, you know, what? So, there's going to be, there's a [00:48:00] number of factors involved, though 1, you'll always hear resources, resources, resources, right?

If we're working you up. I can't work someone else up right so so for example if I'm working you up and your recipient that you know 30 percent 25 percent function, but I'm working you up then it because it's a closed box, then someone else who's recipient might be at 15 or 10 percent function has to wait for their CT scans and so forth.

So the point is, there's it because it's a closed system. Um, we do one thing, it has impact on others so I think everyone understands them. Number two is actually defining a transplant is actually a lot more difficult than you think. So, it seems to make sense, you know, if someone's kidney function declined, then you could transplant them at a certain point.

It turns out, actually, all the evidence to date shows, it was quite remarkable actually, the follow up for a long time thought that earlier dialysis or intervention to replacement of kidney function is better, right? Don't wait until it gets too late. Actually, it turns out the trials have shown definitively it depends on symptoms.

The same patient [00:49:00] could have a level of 10 percent or even 5 percent kidney function versus another patient has a similar level. One may be symptomatic and the other one may be completely fine. And it turns out going by symptoms is probably the best way to just Determine when one should start. If anything, starting sooner actually has downside.

So on the dialysis part, you can see that, right? The access infections, all that stuff. Transplant actually does have a downside as well. If you transplant someone sooner than they need to, they get exposed to immunosuppression much sooner than they need to. And that has a cumulative effect over a lifetime, right?

So if you can avoid that as long as possible, safely. And what would want to do so. So, you know, there's a number of factors, but it totally makes sense from from I think the way you said it is that it should be more time and the and I'm going to come back to my data sort of not rant, but my soapbox is that the more data we have around this issue, the more we can do better prediction around when at a given individual might progress.

So I'm totally in your camp to say, let's do this in a more intelligent way. Maybe earlier is better, but at the same time, [00:50:00] what are the implications for the system as a whole, but better predictions can really help us sort of tailor it more specifically to a given patient recipient, a recipient donor pair.

Very good points. Yeah. I'm wondering if AI technology could help us with things like booking these tests and, you know, prioritizing certain people. And, you know, the Canadian Blood Services has done such a remarkable job with their kidney paired donation program and the algorithms that have been created.

Is there room for AI technology to help us? Book things better. You know, find, um, last minute appointments, prioritize certain patients, all of that kind of thought process of making this system easier to get faster access. And you're absolutely right, Candice, that after one of the low hanging fruit, as they say in healthcare, is using these tools to better manage and, uh, our processes in the hospital in particular, how we book appointments, how we order.

[00:51:00] Uh, tests, how we order supplies, for example, right? So supply chain issues and things like that. So actually our industry and healthcare has really is really behind, I mean, other areas like finance and support, they've really sort of a graced machine learning approaches to doing this. So I think there's a tremendous opportunity to do that.

I agree with you a hundred percent now with these also these large language models that have come out, like cats and PT, which everyone's heard of. It's really sort of also creates an opportunity for patients to be able to interact more intelligently with machines to help them understand their own health.

I think the prospects of using these tools to better health is tremendous. It's a huge accomplishment. And we, we talked a little bit about, um, the kidney pair donation program, and we've had some amazing guests on the podcast who have, you know, been part of that incredible swap, I guess you would call it.

Um, and they just celebrated their thousandth. Kidney pair donation, which is incredible. I'm, I'm wondering when we think about that cross match program and how well it's done. If a pair comes [00:52:00] through the program and they go through the process and they're not a match, um, instead of going to the next person, why wouldn't we prioritize KPD as a first step for somebody so that then they wouldn't have to go through That entire process again, is there a reason why we would then go to the next person on the list or, um, you know, compatibility issues?

Is there, I guess what I'm asking in a very roundabout way is, is, um, are we missing out on transplants thinking about the kidney pair donation program as more of a priority, um, to put people in then as a second option, I guess. A second option to what I just want to understand. I'm to like a direct match.

I guess I would think. Oh, I see. I see. Um, okay. So, yeah. So, um, yes, that's possible. Ultimately, I guess this is the balance between, you know, the, the utility and, and the individual level benefit. Right. [00:53:00] So you're, you're right for, for any given pair. You know, their, their, their goal is to get transplanted as soon as possible.

Having said that, if anything, in general, opportunities for matching is better at the national level than locally. That's why we do this in the first place. And so if they're not matching nationally. The chance of finding a pair locally is very slim. Right? So so that's but that's one of the reasons why we go to the national level is that when you when you have that incompatible compatibility locally, having a much larger pool to find compatibility is increases the chances of success versus staying locally.

So that's one of the reasons why we do. There are some situations where a particular recipient is so what we call highly sensitized, meaning they have so many antibodies, really find it difficult to find them a match, such that they're not finding anyone in KPD either. Then, you know, then it's, it's a, it's a challenging situation.

And the question is, you know, how do you then try to increase that individual's chances further? Okay. And so actually, generally, these individuals, um, I'm not sure if this [00:54:00] is a policy at CBS, but for example, in general, these patients are much more difficult to match. They are also typically also listed on the, on the, uh, HSP, the highly sensitized patient registry.

So that's a deceased donor transplant listing, but it's national as well. So we do everything we can to find opportunities for that individual to receive a kidney. There is also, although this probably doesn't help in the context of the high sort of sensitization issue, is there's also something called, uh, care, uh, list paired exchange.

So what that means is if you're not finding something at the, at the national level, QPD level, there is the option that your donor donates to the waiting list. And then you're given some priority, additional priority on the deceased donor side as well, right? So that there is a algorithm for that. So there are different ways that we could try to improve chances.

But unfortunately, biologically, we hit a wall if one's antibody levels are very, very high. And so to the point where the only way you can get a transplant is essentially to find your genetic [00:55:00] twin. Um, this is a very large question to ask. Um, and I, and I've asked Sylvie a little bit about this as well, but when we think about the big system, you know, often I said to Sylvie, we can think about it as, you know, big walls and barriers in front of us and, um, trying to think of these small steps that we can take to make it better.

What do you think can be done in Canada to better improve access to kidney transplant on a system level? I'm going to just go back again to the idea that we need to know what we're doing and how we can improve. So data is critical. The second one of course is, um, you know, the issue is really around improving opportunities.

And so of course, donation is a major part of that. Having said that we have to balance that perspective investment with getting people transplanted because at the end of the day, we can have many donations, but if you don't translate to transplant, the system hasn't worked. Right. Also at the end of that.

Making sure transplants last as long as possible. You can get people [00:56:00] transplanted, we're not taking care of them, and innovating in ways that allows those transplants to last as long as possible, to the point, dare I say, that we want to mimic the life expectancy of someone who doesn't have an organ failure.

Right? That's the goal, right? Then, if we haven't done that, then again, we've fallen short, and so we need to make sure we make those investments as well, to make sure these organs last a lifetime. Right, yeah. Yeah. That's the goal. Mm hmm. Also, a structure that allows ongoing improvement, right, so, so that we can sort of revisit it and make sure that, because at the end of the day, there's always ways to improve things and so, but we need to have visibility to all those components, and it's quite remarkable how little extra organs we need to eliminate the whitelist.

Right. So if this make, if it makes us a social imperative that everyone understands that this is our, our, uh, obligation, our duty, and our, and not just when we think about obligation duty, we think of it as sort of imposed on us. But instead of thinking that way, just thinking of it as a human [00:57:00] sort of, uh, Endeavor that we should all strive for that.

We should be thinking of donation as part of who we are and what we do, then you know what we can eliminate the waiting list tomorrow. It's quite remarkable. That's the ultimate goal at the end of the day, right? To not have people to have to wait any longer for access. Yeah, for sure. For sure. And also to try to prevent organ failure to begin with.

Yes, that's a very important piece. Right? I mean, yes. Thank you both so much for for joining us today, Sylvie. Thank you so much for sharing your journey and all of the incredible work that you do in community and Dr Kim. Thank you for all of the innovation that you and your team continue to do and for taking such good care of us patients.

It's wonderful to know that we have physicians like you who are, you know, pushing for better systems and better support for us. And thank you, Candice, for the opportunity. Thank you Thank you so much, both of you. We hope you enjoyed this episode of the Living Transplant podcast. If you did, please leave us a review and share with your [00:58:00] friends.

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