

# Behind the Scenes at the Banff CST Conference

[00:00:00] Welcome to Living Transplant, the podcast that takes you behind the scenes of the transplant program at Toronto General Hospital and brings you open and honest conversations about the transplant experience. My name is Candace and I'm the education and Outreach Coordinator for the Center for Living Cord and Donation.

I'm also a kidney transplant recipient. This is where I developed my passion to support others in their journey to navigate the world. Full disclosure, I'm not a physician and I'm not here to give you medical advice. Think of me as your guide through the world of transplant to educate, inspire, peak, your curiosity and fuel your passion.

Living transplant will show you the world of transplant like you've never seen it before.

**Candice Coghlan:** Welcome back to the Living Transplant Podcast. This is a special episode of Behind the Scenes at the Banff CST Conference. The conference [00:01:00] connects members of the Canadian Society of Transplantation with cutting edge science and leading clinical practices that can be used to advance the practice and science of transplantation in Canada.

In this episode, I'm joined by members who presented at the conference. You will hear from Dr. Marcello Cypel about universal blood types. Ghazaleh Ahmadzadeh about the relationship between African Caribbean and black kidney transplant candidates and recipients and their healthcare providers in living donation.

Dr. Deepali Kumar about boosters and antibodies preventing COVID in transplantation. Jeff Green and Ryanna Bowling who discuss a modernized pan-Canadian organ donation and transplantation data and performance reporting system. Dr. Caroline Tait joins me to discuss presumed consent legislation and why engagement of First Nations, Metis, and Inuit health leaders are key to decision making.

Dr. Heather Ross speaks about women in transplant and how to test your [00:02:00] limits. And lastly, I am joined by Dr. Massimo Mangiola, who speaks about the immunology of xenotransplantation. I hope you enjoy this

compilation from presenters at Banff CST. Stay tuned for future episodes and thank you so much for listening.

**Banff Dr Marcelo Cypel:**

## **Dr. Marcelo Cypel-Universal Blood Type**

**Banff Dr Marcelo Cypel:** My name is Marcelo and I'm a thoracic surgeon and lung transplant surgeon here at UHN and I also serve as the surgical director for the Ajmera Transplant Centre.

And so what would, this may be hard to answer, but what would an average day for you look like? Very busy. From from surgeries starting very early on, sometimes transplants, late clinic visits, many patients rounds in the icu, and and also teaching [00:03:00] activities as well as research activities.

Wonderful. And so I have a lab that that has also many students and fellows doing full-time research.

Wow. So thinking about that research you are going to be presenting about universal blood type transplantation. Can you tell me a little bit about your presentation at CST?

Yeah, so we're going to present the data that we actually recently published. But we have done further experiments also since the publication. And what we showed in this study was that actually we could convert organs from blood type A donors to all type. Wow. And, and so they become universal blood type organs. [00:04:00] And the main motivation for this was the fact that oftentimes we have very sick patients on the wait list.

That they can't have the next available organ because it's not the right blood type. And blood type is the first thing we screen when we have a donor to match into the recipient. So if we, if we could transform most of our donors in universal blood type organs, then I think we'll create a much more efficient and equal distribution of the donors to the patients most in need.

Wow, that's, that's remarkable. So if this universal blood type became a reality, would that be another step towards making the, the transplants much more

accessible and easier , for donors to [00:05:00] donate to their loved ones or deceased donation? Could it be used in that scenario as well?

Absolutely. I mean, this could be applicable for deceased donation and also live donation. Right? Because the, the process that we do to remove those antigens from the organ, which classify them as blood type A or B is done after the organ is removed from the donor, right? And so it's, there is no implications for the donor itself. But could have huge implications for, for the recipients.

Again you take the main, the top barrier here for organ allocation. I wouldn't say a barrier here, but the top criteria is actually the blood time, right? Mm-hmm. . Mm-hmm. . So you can, let's say, ignore [00:06:00] that now. Wow. And go to the second criteria, which could be size. Other things that we have to take in account, right?

Mm-hmm. , that's remarkable. I think this is an incredibly fascinating and exciting innovation that you have found here. I'm wondering how far in the future with the implementation of this technology be.

Yeah, so I, I think we'll be able to apply that relatively soon. I mean, this is just to highlight, this is being done in collaboration with some investigators from UBC, University of British Columbia, wonderful.

Who helped develop the, the enzyme that actually cleave the sugar from the cells. And the sugar, again, the A blood type is a [00:07:00] sugar that is on the surface of the, of the cells that cover the blood vessels. The preclinical studies we have done in using human lungs, they have shown that we can remove 99% of these antigens when we reintroduce blood from a different blood type into the organ.

We didn't see any signs of rejection. Right. Wow. We still don't have data to know long term what to be the fact. Mm-hmm. and because it's, it's difficult to have animal models because animals have different blood types. It's difficult to study this in animal models, but we feel that we can start this in the clinical setting by using a subset of donors that have low expression of the antigens to a subset of recipients [00:08:00] that have a low level of antibodies. Right, Right. So be kind of a gradual introduction of this into the clinical practice because those two groups, even if the there is let's say if the enzyme doesn't work, okay. Mm-hmm. there is still ways of treating those patients then they can do well.

Right? So that would be kind of our safety net for the beginning, and I, I believe in 2023 will be introducing this to the clinical arena in this popul.

Wow. That's remarkable. That's fascinating. Yeah. Is there anything else that you would like to share either about this incredible research or a message to the potential recipients or potential donors about what that impact could be for them?

I think the main impact will be [00:09:00] that we'll be able to transplant sicker patients sooner. Because we'll be able to allocate the next organs for them. The other comment I'd like to make, although our work was done exclusively in lungs mm-hmm. , this is applicable to all organs. Right? Right. So mechanism that the enzyme cleaves, the sugar is the same in any organ, and in fact, Recently, a group from the UK has followed our footsteps and have done some pilot studies in kidneys as well without transplantation, just on the preclinical side.

But this is just to show that I think this will come to, to, to our organs in the future and, and will help a lot. I think we'll learn a lot. When we do the initial clinical trials mm-hmm. , But I think the potential as, as a [00:10:00] clinical surgeon that I receive the offers every day. I can see the need for that.

Yes. And, and also not only will facilitate more equal distribution, but also there are situations where, Sometimes we receive a donor offer from a specific blood type mm-hmm and we don't have the right recipient to match for that organ. Right. So those organs are often not used. Right. And so we'll be able then to use also more organs.

Mm-hmm. For transplant that could be discarded in current, the current practice.

Amazing. Some people when they were initially talking about transplant because of their blood types. They were told four to six years or potentially longer for a deceased donation. So this could potentially help those people as well, so that they don't have to [00:11:00] wait as long when they have those different blood types.

Absolutely. I think for kidney, the main impact is exactly that will shorten the wait list time. Mm-hmm. fortunately the kidney, patients, they can still stay on the wait list doing dialysis. It's not a pleasant thing, but they stay. But this is, this is very, the very important, again, because the wait time adds a lot of clients complications, morbidity, and so on.

Mm-hmm. . Now for other organs, like for example, lung and heart. That could represent the difference between being alive or or dying because they can't wait

the one or two years No. Where we're talking about usually months of waits that these people can have. Wow. So I think would be benefits on, on both sides.

Each organ will have the specific benefits. [00:12:00] Mm-hmm. overall, I think the whole transplant field will benefit from this concept. There are still more studies to be done before the, We can say that it's a home run for mm-hmm. , the technology. Yeah. Wow. Recently we had Dr. Humer on the podcast and he talked about the Ajmera transplant Centre's hail Mary, incredibly transformative goal of eventually ending wait lists for potential recipients. And I think listening to you today, it, it's another example of one more innovative technology that Ajmera team and people across Canada have created that are gonna bring us one step closer to ending that wait.

Thank you so much for talking to me today and for all of the remarkable work that you do. We're really [00:13:00] appreciative of having someone like you in our corner. Thank you. Yeah. Thank you for the opportunity for explaining this.

## **Ghazaleh Ahmadzadeh- Relationship between ACB patients and healthcare providers**

**Candice Coghlan:** Up next, I bring you my conversation with Ghazaleh Ahmadzadeh about the relationship between African Caribbean and black kidney transplant candidates and recipients and their healthcare providers in living donation. Enjoy.

**Banff Ghazaleh Ahmadzadeh:** My name is Ghazaleh Ahmadzadeh and I recently graduated from my undergrad at UoT. I have been working. Dr. Mucsi team.

So under his supervision, and I've been doing some qualitative work for the past, almost two and a half years now, I have been primarily focusing on transcripts from African, Caribbean and black patient groups. So I have been analyzing patient transcripts, and I have been talking [00:14:00] to other community members and really listening to their experiences and their challenges and pursuing LDKT, and not just LDKT, but kidney transplant in general and organ donation.

Amazing. Thank you. I'm wondering if you can expand a little bit about that research and tell us about the presentation that you have done at the Banff CST conference and what that all entails.

My presentation today at cst, I was focused on the relationship between patients and their healthcare providers, and as we know, The relationship between patients and their healthcare providers is an integral aspect of their pathway pursuing and receiving living donor kidney transplant and kidney transplant in general.

Basically, in our study, we aim to explore based on the data obtained from our participants in [00:15:00] Toronto, Ontario, the relationship between patients and their healthcare providers and the potential implications. Of this relationship to LDKT, or living donor kidney transplant. Our study highlighted that ACB patients desire a respectful, open, trustworthy, and collaborative relationship with their healthcare providers, as do all patients.

Mm-hmm. .

However, our analysis also suggested that these expectations. More frequently met if healthcare providers are also from ACB communities. And the absence of this relationship may prevent important conversations about kidney health and be a significant barrier to exploring and pursuing LDKT in this population.

In the presentation, you mentioned a very shocking statistic about the difference between white patients and the ACB community [00:16:00] and receiving living donor kidney transplants. Can you talk a little bit about that?

The Canadian data suggest that patients of African, Caribbean and black descent with kidney failure are 65 to 70% less likely to receive living donor kidney transplantation compared to white patients, and this could be due to many, many, many, many different reasons. And in our study we basically wanna see why that is and taking a look at it from a qualitative standpoint. Well, I actually submitted another abstract last year to CST and that abstract was focused on fears of patients, which could contribute to this, to the disparity.

The most recent abstract was focused on the relationship between healthcare providers and patients. So you could imagine that the, the main three, I [00:17:00] guess, subthemes in, in my recent abstract was that. Patients want a more person centered approach. They want a judgment free interaction with their healthcare providers.

They want an increased representation in the healthcare system. So you could imagine that if a patient is not comfortable with their healthcare provider, if they are scared of, if they're afraid of being judged or coming across as uneducated. And so for that reason, they withhold their questions that.

Has an implication in pursuing LDKT or kidney transplant for that matter. And, and this is especially important for the ACB population, they have said again and again in many, many, many of the interviews, that they feel way more comfortable with a healthcare provider from their own ethnic background and somebody that [00:18:00] looks like them and they.

Break things down with them and be themselves when talking to them. So again, that's another aspect that's very, very important in, in the relationship between healthcare providers and patients. That is why so many of our participants have recommended or wanted greater diversity within the healthcare system.

I'm wondering, If you have any ideas and if anything has come forward in your research about how to make a change in our healthcare system to make living donor kidney transplant more equitable and more accessible for all patients.

Yeah, absolutely. As I guess that's also a future direction for us in our research group. So we were hoping to use the understanding of the experiences. These expectations and desires of, of ACB [00:19:00] patients to contribute to the development of interventions to improve equitable access and utilization. And we are actually currently working on a website that is meant to provide all the information necessary regarding kidney transplants, living donor kidney transplant disease, donor kidney transplant, organ donation, and we are actually co-developing this website.

ACB community members and our ACB partners. So we are getting their input, their stories, their experiences, challenges, and we are hoping that future patients or even current patients could make use of this website. We are hoping to cater this towards the ACB community. Something else that could potentially be done is healthcare providers training to improve their relationship with their [00:20:00] patients. This training could focus on improving educational methods to skills to enhance person-centered care for physicians and which emphasizes creation of culturally safe environments within the healthcare.

Thank you so much for all of that information. I'm wondering if there is anything else that you would like to share with the Living Transplant podcast listeners?

It was an absolute pleasure to be on your podcast. I would really recommend for people to check out other episodes on this podcast and to check out our website nefros.net. We have more information regarding our future, future work, recent publications action project, and I think it's a great resource for, for everyone interested to check out. [00:21:00] Fantastic. Thank you so much. And before we leave, anyone who is listening who wants to learn more about transplant and more, Stories from the ACB community and research from the community we do have an ACB Organ Health YouTube channel through the Center for Living Organ Donation that you can check out as well.

Thank you so much for joining me today. I really appreciate it. Your, your presentation today was fantastic and I'm happy that the listeners get to hear a little bit about it.

Thank you so much. It was my pleasure.

## **Dr. Deepali Kumar- Boosters & Antibodies, Preventing COVID in transplantation**

**Candice Coghlan:** Covid has dominated a lot of our conversations lately, but one perspective that we always appreciate hearing is that of our physicians and how to stay safe.

Please enjoy my conversation with Dr. Deepali Kumar about boosters and antibodies and preventing covid in transplantation.

**Dr. Deepali Kumar:** Welcome, and thank you so much for joining me.

Great. Thank you so much for having me. I'm wondering if you can introduce yourself to our listeners and a little bit [00:22:00] about what you do and, and who you are.

Sure. So hi everyone. My name is Deepali Kumar. I'm Director of Transplant Infectious Diseases at the Ajmera Transplant Center in Toronto. And I'm professor of medicine at the University of Toronto.

So what I do on a daily basis is I see patients. Who've had transplants and now have infections and prescribe antibiotics and antivirals and antifungals. And I also have a research program where in the last couple of years we've primarily been working on COVID research.

Amazing. Thank you. That is a topic that I think most listeners are going to be very interested in hearing about today, so thank you so much.

I'm wondering if you could tell us a little bit about your presentation this week at Banff.

So at this COVID session, which. Which I'll be presenting at during the CST conference. I'll be discussing two main things. [00:23:00] The first is up to date information on covid vaccines and which types of vaccines are recommended for transplant recipients for best protection.

I'll be showing some of the research that our group and others have done that leads to making these recommendations. And of course, I'll be talking about how we're going to use the newly approved bivalent vaccines. And then the second part of my talk will be on something called passive immunization and how we can supplement vaccine immunity in transplant recipients with an injection of antibodies.

Oh, that's, that's fascinating. How does that directly impact tra transplant patients and thinking about our vaccines and how many we've had and thinking about the number of doses that we've been told to get I know it's a, a very large topic to think [00:24:00] about, but I'm wondering if you could talk a little bit about that impact to, to our community.

Sure. So one of the most important things that came out of our research was in 2021, we, we published on the third dose of Covid vaccine. So if you re recall back then, the recommendation was that everybody get two doses of vaccine. Mm-hmm. and at UHN we did a trial that showed that the third dose of vaccine in transplant recipients was a must and very necessary to get good protection.

And because of that, the recommendations changed in Canada as well as the United States and actually across the world. The primary series for transplant recipients should be three doses. Now, following that, we've been looking at four doses and five doses of vaccine, and we're [00:25:00] leading a large Canadian study that is following over 500 transplant recipients to see how well the fourth dose and the fifth dose works. And what we've found so far is that yes, you definitely get a boost in your antibodies after fourth and fifth doses, so it is very important to keep up to date on those booster doses.

Amazing. There's been a lot in the news lately about Evusheld and the Bivalent vaccines. I'm wondering if you could speak to those about how they impact US transplant patients.

So, the Bivalent vaccine, as was recently approved in Canada as well as the United States. And this is the same vaccine that we've had. Originally, so this is an mRNA vaccine, but they've changed it a little bit to include the omicron strain.

Okay. So it actually includes half of the original strain, or half half of what it includes is the original strain, and the other [00:26:00] half is an omicron strain. And so what we hope from this vaccine, That that transplant recipients would get a better antibody response against omicron. That's what's been shown in the general population and our research group is now moving forward to look at by valent vaccines and how well they'll work in the transplant setting.

So the recommendation now is, That no matter how many booster doses you've had that you should receive a dose of the bivalent vaccine three to six months after any previous booster dose.

Okay. And then Evusheld, how is that different from the vaccines?

So Evusheld is something that we call passive immunization.

So when you get a a normal vaccine, your body has to process that vaccine and make an immune response and make antibodies. Evu shed [00:27:00] is just antibodies, so it requires no processing. So you can just get an injection and You Within a couple of days you have an antibody level, so your body doesn't actually have to process it like it would for a vaccine.

And so Evusheld has been found to be effective in reducing the rate of omicron infections in the BA one and b a two wave. We are still waiting for data to see how well it will work for the BA five wave, which is the, the current wave. Mm-hmm. . But we hope that it will work in a similar fashion. So one thing with Evusheld is that it is not a replacement for vaccination. I think that's something that's important to emphasize. You still need to get your vaccines, but if you want that extra layer of protection, then Evusheld [00:28:00] would be the way to go.

Okay, so. From a transplant patient, re processing all of this. I've had five doses. So really I should just stop counting my doses and get the bivalent vaccine three to six months after after the, the current vaccine that I've had. And then Evusheld is also a great booster for, for me as well to think about getting.

Correct. So we have to, we do have to stop counting now. I think we're moving in the direction where, what we need to be thinking is, are we up to date with our vaccines?

So in the past it was, well, have you had two doses, 3, 4, 5 doses right now? We, we are moving towards just saying, am I up to date? Which essentially means have you had a booster in the last six to [00:29:00] 12 months of the latest vaccine? And in this case, being up to date would mean having that booster of bivalent vaccine in your system.

And so, so what would happen is the priority is, is getting the vaccination. Mm-hmm. . Then if you want that additional layer of protection, wait a couple of weeks after your last booster and then go ahead and, and get the Evusheld shed. Okay. Now, I, I will say, and I will mention this in my presentation later on as well, that Evusheld is not available in every province. Right? Each province has different recommendations and different criteria for administering Evusheld. So I think it's important to find out your province's recommendations regarding Evusheld.

Fantastic. Thank you. That is a great overview of, of such a [00:30:00] huge, massive topic and a lot of hard work and, and research and I think from the perspective of all of us transplant recipients. I, I just wanna say thank you for all of the hard work that you've done and that your team has done at uhn, because throughout this process, It has been very scary and very isolating to be a transplant recipient through the pandemic, but knowing that we have. Researchers and doctors and whole team behind us who are really working towards making sure that we are safe has made it a lot more manageable for us.

So thank you so much for everything that you and your, your team has done. It's really greatly appreciated.

Thank you. Mm-hmm. . And I'm wondering if you have anything else that you would like to share with our Living Transplant podcast audience?

Well, I'll just say that Even after you've gotten your vaccines and have your Evusheld, I think it's still [00:31:00] very important to take those precautions.

If your immune system is suppressed, it is still important to avoid those crowds and wear a mask and protect yourself. I think we're just going to have to learn to live with Covid. It's not going away anytime soon and I think it has established itself in the population and we'll probably continue to circulate.

We'll probably see waves in the future. And so, so I think personal protection will still be really, really important.

Fantastic. Thank you so much. I'm so grateful that we've been able to steal you away for a little bit of time to bring all of this amazing research and information to patients and families.

So thank you so much for being with me today. Thank you.

## **Jeff Green & Ryanna Bowling- Pan Canadian Organ Donation & Transplantation Data Reporting System**

**Candice Coghlan:** The next discussion I have for you is with Jeff Green and Ryanna Bowling who discussed the development of a modernized pan-Canadian organ donation and transplantation data and [00:32:00] performance reporting system. Enjoy.

**Pan Canadian Data System:** Welcome both of you. Thanks. It's great to be here. Awesome. Likewise. Thanks for having. I'm wondering if you can introduce yourself to our audience, Ryanna sure, I can start. My name is Ryanna Bowling. I'm a program lead at the Canadian Institute for Health Information. CIHI for short. And I'll pass it over to my colleague Jeff.

Thanks Ryanna hi everyone. And I'm Jeff Green. I'm the senior director of our organ donation and transplantation program at Canada Health Infoway. Fantastic. And so can you tell me a little bit about your presentation that you've done this week at the conference and what that is all about? Sure. Maybe I'll take a first stab.

So yeah, we were really excited to be a part of the the meeting this week. And our presentation was focused on a Pan-Canadian [00:33:00] project that our two organizations CIHI and Infoway are co-leading on behalf of Health Canada. And it's a project that's really focused on really the modernization of the way that data is managed and reported across the organ donation and transplantation spectrum.

So what that really means in terms of the work we're doing is we are procuring and implementing point of service solutions. So the, the, the software that that clinicians use to manage their workflow both within organ donation

organizations as well as in transplantation centers, in acute care hospitals across the country with the main purpose being.

That they will collect consistent data that will then be digitally seamlessly submitted into a newly created pan-Canadian [00:34:00] ODT data repository that's gonna be managed by CIHI Ryanna's organization on an ongoing basis. And that will have data from ODT activity across the country that can then be used to report on performance on an ongoing way.

And and use that to support quality improvement and efficiency initiatives. Fantastic.

What has the progress been from the past year of what you've implemented so far?

I think I can cover that for you and Jeff, feel free to chime in as well. Yeah, you bet.

So in terms of CIHI's progress on work stream activities, which are done in parallel to info ways we've made significant progress to date on developing national data standards for deceased donations, living donation and transplantation. All readily available on our project website, so that's very exciting work [00:35:00] and it really lays the foundation for the standards and the data that we're gonna collect, embedded at point of care solutions that Jeff spoke about. And then that will feed into the pan Canadian indicators and the important measures we're gonna be able to capture and report on from the CIHI side.

And over to you, Jeff, for the progress and info way? Yeah, sure. So at the same time that CIHI's been leading that really important work we've been collaborating with stakeholders from across the country to work on a public procurement process to identify a solution like a technology solution for management of deceased donation data.

So I'm happy to report that we actually completed that initiative last year and we were able to announce that Transplant Connect was the preferred vendor identified through our process. And they have a product called I [00:36:00] transplant. That is going to be deployed to a number of provinces across the country.

So now we've moved from that sort of planning process to getting ready to really move into to implementation within, within specific provinces. Oh, that's fantastic.

And Candice, maybe I'll close off with the other work stream that CIHI is leading, which is the development of the Pan Canadian indicators.

So over the past year, we've led extensive engagement. So we've met with over a hundred ODT members from across the country, and this ranges from clinicians, decision makers ministries of health representatives, and of course patients, families and donors to seek their perspective on what's important to measure and what's going to go into the performance reporting that will be in CIHI.

So that's an important progress today. We've completed that work and now we're moving to the exciting phase of developing all those indicators for reporting. [00:37:00]

Wow. That's a lot of work for, for you guys. , we're busy. And so I'm wondering as well, if you could talk to me a little bit about the data and how all of this would contribute to making transplant and transplant data more accessible and, and equitable for patients and, and providers across the country.

I can speak to that Candice. So when we think about it, a modernized O D T data and performance reporting system is really needed. And because we need that, it's gonna be able to improve the quality and efficiency of our care, equity of access to transplantation for all of Canadians, really to enable better patient outcomes for both transplants, recipients, and of course living donors across Canada.

Wow, that's amazing, . That's fantastic. And so I'm wondering if both of you have anything that you'd like [00:38:00] to share, either about the Banff presentation or about your organization as a whole to our listeners that could provide them maybe some insight into what you do or just a message of, of hope of what's to come.

Sure. Maybe I'll I'll, I'll start and Ryanna, I'm sure you'll have comments as well. I think it's been a real, it's been a really positive experience for us to attend the meeting in Banff. I think it was great for our project to have exposure to some new people that weren't as familiar with the work that we were doing at the same time.

It was nice reassurance how many people really already were aware of of the work and had heard of it and wanted to learn more. So that was really encouraging. And I think Our I, I know I speak for our whole project team when I talk about how meaningful it is for [00:39:00] us to be working on this project and such a, such a tangible impact on this important part of our, of our healthcare system, and knowing that it's going to lead to improvements in efficiency of the system.

But most importantly in terms of Patient outcomes on the transplantation side and and improving the the performance on the donation side and speaking to some of the things that Ryanna mentioned around missed donor opportunities and important, important metrics like that.

So, and I can also speak for myself personally as the son of a double lung transplant recipient, that really means a lot to, to me, to know that we're that we're helping in that way. Incredible.

So from my perspective, I'd wanna say an echo of thanks to all those that we've engaged with from the ODT community over the past year and, and [00:40:00] previous to get to this point. We hope that the updates and the progress we've shared can give you a picture of what that end goal of a a world leading modernized ODT system is gonna look like and how that's potentially provide knowledge and information to those who need it to seek it when, when they're looking to learn more through their transplantation or their donation journey. So more exciting work ahead to come. It's it's a process and there's more work ahead for sure, but we're hoping for continued success, continuing engagement with patient families and donors to seek your perspective, especially when we think ahead to the public reporting that that will come.

In the future. Wonderful.

Thank you both. And if people want more information about your organizations or about this project, where can they go to find that? Thanks, Candice. All the latest updates are available on our project webpage, which is the [00:41:00] [CIHI.ca/odt](http://CIHI.ca/odt) and also available on Infoways project webpage as.

Fantastic. which is [infoway-inforoute.ca/odt](http://infoway-inforoute.ca/odt). Perfect.

Amazing. Thank you both so much. I'm so grateful to have had you on the podcast and thank you so much for presenting all of this very important information to us. We really appreciate it. Thanks. Pleasure. Thank you.

# Dr. Caroline Tait- Engagement of First Nations, Metis & Inuit Health Leaders in Key Decision Making

**Candice Coghlan:** I was very lucky to be able to steal our next guest away for a few minutes. In between sessions. Dr. Caroline Tait joins me to discuss presumed consent legislation and why engagement of First Nations Metis and Inuit health leaders are key to decision making.

Take a listen.

**Caroline Tait:** Welcome, Dr. Tait.

I'm Dr. Caroline Tait. I am the research leader of the First Nations and Metis organ donation and transplantation network. It's based in Saskatchewan. I am a professor in the Department of Psychiatry at the University of [00:42:00] Saskatchewan, but moving in January, 2023 to the University of Calgary to become a Canada research chair focused on inequities in Indigenous.

Wow. Fantastic. Yeah, I'm excited. That's amazing. . I'm wondering if you could talk a little bit about the presentation that you'll be doing.

Yeah, I'm, I'm really excited about the presentation because I think what the presentation will do I, is that it will draw attention to issues for Indigenous people that maybe others haven't thought about.

Mm-hmm. . So The main focus of, of, of the presentation begins with Nova Scotia and the Nova Scotia government, which has passed deemed consent legislation and, but did not consult with Indigenous peoples prior to the legislation. So what does that mean? And, and so in the talk I, I, I refer to what we call free and informed consent and, and with Indigenous peoples in Canada, that the government does [00:43:00] not have a duty to consult on legislation, on health legislation with Indigenous peoples.

There's no legal reason that the governments have to consult with Indigenous peoples, but part of good government. And good policy is really to engage Indigenous peoples. But if you look at the UN declaration on the rights of Indigenous peoples, it clearly states in Article 19 that consultation should be done.

And, and so I refer in my talk to the rights of Indigenous peoples, really trying to make a distinction between the ways in which many governments and, and medical. Health related issues are, are, are seen that Indigenous people are an ethnic group or they're a vulnerable group, or, or they're a group, a marginal group and there's all kinds of, of language that's used.

Mm-hmm. , but first and foremost, Indigenous nations. First nations, Metis nations, Inuit nations are nations [00:44:00] and they hold rights and they hold certain sovereignty over, over their, what happens to their people. Mm-hmm. and, and certainly in research, we have a lot of discussion and have for years around data sovereignty.

Mm-hmm. , and this applies as well. As we move forward and we start to look at the development of policy and legislation. Mm-hmm. . And so the talk that I'm giving First of all draws, draws upon that. The second thing that it does is that it, it talks about where are Indigenous people in the organ donation and transplantation discussion.

Right. So they're, they're basically absent, although there's some very good researchers Dr. Jag Gill and, and Dr. Aviva Goldberg and others that have been working in this area. Again, their research is, is just. in the infancy. In some ways, I think they would agree with me that they're, they're doing their best to look at what are, what are the barriers, what are the gaps?

Mm-hmm. how do Indigenous people [00:45:00] understand organ donation and transplantation? So even globally, there's very little literature. Mm-hmm. . So, so that's a, that's a real challenge. But I draw attention to the disparities. And so what we have is, we have geography, of course, as being a main challenge where people live, how they access services, and I can't remember the name of the author, but there, there's an article that, that I, I've quoted where the, the author points out something so important that where you live is the center of your universe, right?

That's what's normal. Mm-hmm. . So if the north is normal, then, then we need to start thinking about patient centered care. In the north. Right. Not patient centered care from this distance, and what we have with, with transplant programs is that they're largely I mean urban based, big urban centers mm-hmm.

and there's a shortage of organs. So if there's a shortage of organs and, and your work is in a big urban center, [00:46:00] It's really difficult to be concerned about people in, in remote regions and all the challenges that they face. Right.

So, so that does not mean that Indigenous people in northern and remote regions do not receive transplants.

They do. Mm-hmm. and the people that I've talked to in Saskatchewan that have received transplants have, have really not many negative things to say about their journey. Mm-hmm. , but most of these individuals were people who are employed. They're, they're, they're people who, who are better off in our communities.

Right. So we don't know. And that's where there's this huge data gap. Mm-hmm. . So we don't know right now how many people who are Indigenous require a transplant. We don't know how many people are being placed on the transplant list, and more importantly, how many are not being placed on the transplant list and the reasons why we don't know whether Indigenous people are receiving transplants the same as everybody else.

Mm-hmm. or whether there [00:47:00] there's certain gaps. I wrote a paper that was came out in the Circumpolar Journal, the International Journal of Circumpolar Health in 2022. That, that talks about the intersection of utility. Mm-hmm. and, and equity. Mm-hmm. . And, and so this is really important when we're talking about deemed consent legislation.

Right. So, so what we have with deemed consent legislation, it's a couple things and, and I won't go into any more detail about the equity and utility, but, but I'll try to pull it into to why it's important in the time we have. So if we're looking at organ donation and transplantation, we don't have a lot of information about the ways in which About the barriers that exist.

Mm-hmm. . And so but when it comes to, to organ donation, there are a few things that we know. We know that Indigenous people tend not to be organ donors. Okay. And that's for a lot of reasons. And, and the one thing is that to be an organ donor [00:48:00] when you live in a remote region I mean, there's a lot of things have to happen for you to be able to be a donor, right?

Mm-hmm. . So you have to be in a southern Hospital, you have to be certain conditions need to happen. So there's certainly some of that. But, but there are cultural issues, although the cultural issues in the literature, at least, and in my discussions with people and I, I discuss with people every day in our communities about whether.

What they think. So it's not research data, but, but just in informal conversations, I'm always raising the question of have you ever considered to be

an organ donor? What do you think about organ donation? And there's a real mix from people coming back where there's people who feel very strongly that if I sign my organ donor card, if they know that I want to be an organ donor and I come into the hospital and I'm in an emergency, Place that I may not be given the life saving care that I need, right?

Because they want my organs right now. Transplant people, [00:49:00] people in transplant programs will argue, okay, that's not the way it happens, right? But regardless of the way that it happens, if people perceive this to be an issue, and so why is it that they would perceive it to be an issues? It's because of history.

It's because that there's times where the government, the church, the healthcare system, and we just saw the, the, the example of Joyce Echaquan in Quebec and Brian Sinclair in, in Winnipeg, two cases where people, we avert racism mm-hmm. and, and so we know that it happens. . And so not to say that, that the system is, is, is entirely racist.

Mm-hmm. , that's not what I'm saying, but racism does occur, but also the perception of racism is just as important. So, so if you have people who perceive an unsafe healthcare environment, well of course organ [00:50:00] donation, taking your organs it's not surprising that people would be really hesitant to sign their donor card or to become a, to, to notify people to become an organ donor.

Mm-hmm. . So, so that's one thing. The second thing. It goes back to that equity and utility question and, and so if we have. Are if, are we looking at the legislation through an equity lens? And if we're not, what could happen? Mm-hmm. . So is there the risk, and, and this is I think the, the most salient point of, of the talk is, is there a risk that we will end up with more Indigenous people through deemed consent becoming organ donors?

But if we don't address the equity issues, that there won't be an increase in the number of Indigenous people receiving organs. Right. Because unless the equity issues are addressed, Indigenous people will continue to be excluded from transplant lists because of, of [00:51:00] non-compliance. Mm-hmm. essentially non-compliance and non-compliance is, is very interesting because it, it sounds.

It's something intentional by the patient, right? Mm-hmm. , the non-compliance can be that you get stuck in two, two storms in which you miss two appointments, right? And you can't get you your appointment. So from the point of view of someone who's deciding who should get an organ over other people because there's a shortage, that decision always is, is to be made.

Are you going to choose the person who postoperative might not be able to adhere to the regime? After the operation or, or who haven't been able to make the appointments. Mm-hmm. . So I don't think that any of these are easy decisions, right. Or easy considerations. But what we really need in the context that we're working is to try to find ways to, to better collect data mm-hmm.

so we can actually answer those questions that I outlined. [00:52:00] Because without answering those questions, even in terms of racism I can argue that there's racism in the system and if somebody says to me, Show me there's racism and organ donation and transplantation, I actually can't show that to you.

I could show you maybe a case study or two of people who felt that they, that, that, that they experienced racism. Mm-hmm. . But one of the ways that you can look to see if there's a bias within the that's based upon the identity of the person being Indigenous, is to break down Inuit, Metis and First Nations, and look to see who is being placed on transplant lists, right?

Mm-hmm. so, So it appears that when Indigenous people are on transplant lists, they receive transplants at the relatively, they may be maybe not as frequently as other people, but, but that they are receiving transplants. Mm-hmm. . So that brings us then to the question of what about the people who don't make it on the transplant list?

Right. What happened to them? [00:53:00] Why weren't they placed on the transplant list? Mm-hmm. . So I think the deemed consent legislation that equity piece where we could see more Indigenous people as organ donors, but fewer receiving . Right. And then the other thing is just general trust in the system. So what happens if Indigenous people decide that they wanna push back against this, that this, that they would prefer for an opt in rather than an optout system and, and doesn't opt in or an optout system, a deemed consent system in terms of free and informed consent. So if you, if provinces start like, like Nova Scotia to implement this without proper consultation mm-hmm. , then what you have is you have a breach of this free and informed consent according to Article 19. Now, I may be over exaggerating.

Of course it would have to be sorted out through legal [00:54:00] people who would know. Mm-hmm. . Just on face value, it looks like it's a valued a valued argument. And so in that way, you may have this backlash towards transplantation that may in fact have the opposite effect of what we want, which is we want more Indigenous people to want to become donors.

Mm-hmm. , we want more Indigenous people to receive organs. And that maybe with Maybe with consultation and inclusion of Indigenous people in the deemed consent legislation discussion, that then we could look at it through the equity lens mm-hmm. to make sure that, that the legislation includes certain considerations around equity that I don't believe are there right now.

Wow. That's a lot to think about. . Oh, thank you so much. I feel like we could do a four hour podcast on this episode or this issue alone. And I will definitely be asking you to join us on a full length [00:55:00] podcast, so look for that email. But I'm wondering people who are listening today who want more information about what you're talking about today and then all of the things that you've brought up, is there a place where we can find the publications that you spoke about? Or if somebody is just generally interested in what you've talked about, where can they get more information?

Yeah, so, so the deemed consent paper is it's been through peer review and it's been accepted with revisions.

Mm-hmm. , so it's in the stage of, of the journal looking at the revisions. So I, I assume it will be published, but I don't, I don't wanna jump the gun off for sure, but it would be coming out in the Lancet America. So there's different Lancet journals, and this one is in the America. So and there was, it was positively reviewed. So, so I think that, that, that's important. The other article is in the Circumpolar Health Journal, which is looks at [00:56:00] utility and equity and, and all of those issues. And, and again, points to the ways in which through the system, Indigenous people can be disadvantaged. Mm-hmm. . And then of course, as I said, there's the work of, of Jag Gill and Aviva Goldberg and others.

There's this emerging literature, but also I think if people are interested to look at the kidney literature mm-hmm. , so not, so not necessarily the organ donation and transplantation literature, but a lot of the kidney literature really speaks to, to those issues. Right. Speaks, speaks to the issues of of barriers to caring gaps, gaps in services.

Fantastic. Thank you so much. I really appreciate your time and letting me snag you between between sessions so you so much. It's amazing.

## **Dr. Heather Ross- Testing Your Limits**

**Candice Coghlan:** During the Banff CST award ceremony, Dr. Heather Ross was presented with a lifetime [00:57:00] achievement award. To my excitement,

I was able to speak with her about women in transplant and how to test your limits.

**heatherross:** Welcome. Thank you, . So if you could introduce yourself to our audience Sure.

And tell us a little bit about yourself.

So I'm Heather Ross. I'm former head of the heart transplant program at Ajmera. And now I'm the head of the division of Cardiology at the Peter Munk Cardiac Center. Still a transplant by heart. Can't can't change the roots that sort of gets in there and sort of is part of I think the fabric of who we are. But yeah, I'm 26 years uh, into the job and still love it.

That's fantastic. Can you talk to us a little bit about what you're going to be presenting tonight? So, I was asked to speak about women in transplants and. I've had this opportunity over my career to merge what I love to do in life, which is adventure and expedition travel.

And my job, and it's [00:58:00] something that we call Test Your Limits. It was founded in 2000 and and six. What's really special about it is that we have a heart transplant recipient, Dale Shipham who comes and often Dave Smith, who's a kidney transplant recipient. They're 23 and 25 years out from transplant respectively now.

Oh my gosh. And so I, the, the journey that I've had with them and on these Test Your Limits trips, of which there's now been nine Wow. In many ways serve as a metaphor for how to not just survive, but thrive. Mm-hmm. in the field of transplant. And I think it's, it's not strictly a, a woman issue, but given that on many of these expeditions, I've been the only woman, in fact, on most of them it, it does speak to me about some of the key things that you have to think about in order to succeed.

Mm-hmm. . What are some of those things that, that we need as women in transplant or in general, I guess in the world?

So I think the [00:59:00] Perseverance. Mm-hmm. . So certainly early on especially in the field of cardiology, which is a very male dominated field, there were times when you're working hard and in some ways feel that you need to work more, do more, succeeded more to be.

At a level playing field, So mm-hmm. , the, the idea of perseverance and, and that comes across on some of the trips that we've had where it's a kind of grueling day in, day out. You just put your head down and, and, and do what needs to be done. So perseverance is a big part. Mm-hmm. I also think that enjoying the journey and I think I watched many of my colleagues who get maybe a little caught up in some of the challenges that are happening and forget that this is still their journey and their life. Mm-hmm. , it is more a vocation, I think, than a job and you want to make sure that you are enjoying it. Mm-hmm. . So trying not to sweat some of the small [01:00:00] stuff and be focused on, on the bigger goal.

Mm-hmm. . And a lesson that I learned a long time ago, which is still one of my quotes is a goal without a plan is just a wish. Mm-hmm. . And so it, it is sort of setting those, those goals, but making sure you put everything that you need behind them mm-hmm. to succeed them with them. Right. And as my mom always said, once you've made a decision, make it the right decision.

So try to actually, again, getting back to that perseverance and, and, and working, working towards the. Amazing. Thank you .

Thinking about that with transplant patients, we, we go through, an insane journey either, whether we're starting from a crash start or if we're years and years until we eventually need these therapies and transplant.

In my case, it was kidney and I was a crash start. So thrown into it without any knowledge. How do we kind of take those ideas [01:01:00] through some of the hardest times of our life and apply, like what you do on that mountain mm-hmm. into those day to days that sometimes it can be hard to even get outta bed for some people.

Yeah. So I really think walking a mile and some of these shoes is is a huge part. As a, as a physician or healthcare provider mm-hmm. , having compassion and trying to see things through somebody else's eyes. And so through these journeys, I myself have had pulmonary edema on one of the mountains. And another one of our trips we were stranded with bad weather waiting for the chopper to come in and rescue us. And you start to think about what it feels like for a patient to be on that journey. And I experienced these things for brief moments in time, whereas the patients, that's their existence mm-hmm. until transplantation. Yep. And I think having had those experiences, which were pretty profound, even though [01:02:00] they were short lived, of course it gave me a much bigger perspective on what the journey might be like.

So I do think. And I said it last night, I, I think it's just that I think the CST has done a really good job of crucially engaging the voice of donor donor families, recipis, persons with lived experience, like really understanding that journey because if we can, then I think we can do a much better job preparing people for it. Mm-hmm. .

Fantastic. And you were just awarded with an incredible honor. Congratulations. A lifetime achievement award. That is fantastic.

Yep. Wow. That was that was very special. So it, it, way back in the day when I, when I came to Toronto a number of senior people at the time who are sort of legends right now in the, in the field.

So Ed Cole and Gary Levy supported and mentored me. And I [01:03:00] got involved in the CST and I actually met through was president of the CST and the cst, and my time with the CST opened a tremendous doors in it at an international level. So I owe a debt to the society. So it was, it was an incredible honor.

Congratulations. I'm wondering if you can leave us with two, two pieces of advice, One piece of advice that you would give to female professionals, I guess in general, and then maybe a piece of advice for our transplant community as a whole.

So, I, I still think mentorship is probably one of the single most important things, and I think men do it differently. So there's sort of that washroom mentorship that happens, or golf mentorship that happens. Mm-hmm. , I think women have to be more particular in ensuring that they get the mentorship from multiple levels for multiple different reasons, cuz different mentors can provide different advice.

I still think mentorship [01:04:00] is crucial and I, I know that I benefited tremendously from it. Mm-hmm. and as a mentor have actually benefited. Because I learn constantly from the people I'm mentoring, right? So I still think mentorship is crucial. I think it for the, those waiting, I think it is just so important to also get peer support and get that support from other recipients. Mm-hmm. and other people on the waiting list. What I've seen is that that's grown since I started in transplantation. Mm-hmm. and only a transplant recipient knows what it's like to have a transplant. Mm-hmm. , I can be involved in the care of patients, but I don't really know what it's like despite having had some interesting experiences mm-hmm. but recipients do, and I think that peer

level support is crucial. So if you're a patient and you don't have it, ask for it. Mm-hmm. , because it is tremendously be.

Fantastic. Thank you so much. And I just wanna thank you as well [01:05:00] from the patient body as a whole. I know I don't speak for everybody, but it's not every day that we meet physicians like yourself who try to put yourself in our shoes.

And so thank you for, for doing that because it really does make a difference in, in our care and making us feel like we're, we're worth what we're going through and that there's somebody out there who's got our backs.

So well thank You Dave Smith and Dale Shippam them are been tremendous mentors for.

So hopefully I'm continuing to learn on that journey to be better at what I do. Amazing. Thank you so much. You're welcome.

## **Dr. Massimo Mangiola- Immunology of Xenotransplantation**

**Candice Coghlan:** Lastly, but certainly not least, I bring you my conversation with Dr. Massimo Mangiola about the immunology of xenotransplantation, which in this context is the transfer of solid organs from pigs to humans.

**Massimo Mangiola final:** Welcome, Welcome. Thank you, Candice, for having me. It's a pleasure. Thank you so much. I'm wondering if you can introduce yourself to our audience.

Sure, sure. My name is Massimo Mangiola. I'm a transplant immunologist and [01:06:00] I work at NYU Langone Health in New York City. And my job, my bread and butter, if you wish, is the compatibility. So is the determination of compatibility between a patient and a donor. Any organ included bone marrow transplant, face, hands, NYU is a very busy and challenging place.

So I'm challenged by pretty much any type of transplant. So what I do every day is to compare a patient, donors to determine whether there is risk of, of proceeding with transplantation.

Fascinating. At the Banff CST conference, you discussed the immunology of xenotransplantation. Yes. Which was thrilling and fascinating for me to get to sit and listen.

And a lot of it, of course went over my head. It was, it was wonderful. I'm wondering if you could explain a little bit about what xenotransplantation is.

Absolutely. My pleasure. So, [01:07:00] xenotransplantation is the transplantation of non-human organs in humans. In this case you transplantation is the transplantation of pig organs into human.

Now of course you wanna say, why would you do though ? Very good question. Very good question. So, as there is a, a very large discrepancy between the patients are waiting organ transplant and in available organ. And this discrepancy, it doesn't seem to be reduced over time. And that is because the system unfortunately relies on somebody to die, for somebody else to have a second chance in life.

And, and also, unfortunately, so the living donation of certain organs, of course, like a kidney or liver, It is not ramping up and in, in some, it's not because there are no [01:08:00] living donation. It's that the, the majority of patient and donor are emotionally connected, and so those are like, but there is no increase in altruistic donors.

Those that just want to give an organ to a complete stranger. Mm-hmm. and. Because of that, we, we have to think outside a box, right? And, and we say like, how can we, how can we help these people? Considering unfortunately so Candice that some of our patients don't ever get to the finish line. They, they stay in the way list for so long and then unfortunately we lose them.

And, and they never had an opportunity to, to have a, an offer. So for those type of, especially for those type of patients, so they highly sensitized, they broadly sensitized against HLA antigens. We have, it's our responsibility think outside the box. And NYU Langone has always been pioneering in [01:09:00] these changes in, in the transplantation world.

And our our leader, Dr. Robert Montgomery, has started a long many, many years ago to, to work on this project of xenotransplantation. We have successfully transplanted in a deceased model. So it is individual that has, that was brain dead and donated the, their body to research. Mm-hmm. and, and we wanted to test is in fact through that we can put a kidney organ into a human. And those, these organ is not rejected immediately. And, and last year we did

two pig kidney transplantation. And this year we did too heart pig heart transplantation. So we know now that, that it does work. And now we, we are approaching the immunology of transplantation, which is [01:10:00] what is going the, the patient, your immune system? What would your immune system do? Mm-hmm. . When we put a pig organ, cause we already know that there is rejection between human to human, so you can kind of guess it that there will be even much so with pig and human. So my job as a transplant immunologist in this project is try to figure out how do we study and how do we control the immune system in xenotransplantation.

Wow. From my perspective, since I'm nowhere close to an immunologist, Listening about changing certain hormones and genes and pigs to make them smaller and as well as modifying the antibodies. That's a, that's a big thing to do.

And, and you've been doing it for, for a while now. Would these changes make those pig organs less likely to [01:11:00] reject in a human.

That's a very good point. Yes. The short answer is yes. I mean, can. Let me tell you a little bit more about it. Yeah. So the, the, the choice of, of pigs as a source of non-human organs is for many reason, one of the reason is that there is a, it's, it's a readily available animal right there.

The physiology of the organs actually is very similar to that of the units compared to other animals. Okay. But as you. They, they grow a little bit larger than us. Mm-hmm. , and also, as you mentioned, the, the organs, the pigs in particular, like other animal, they have some we would call antigens that, that we actually don't express.

So our immune system is prepared against this antigen. [01:12:00] And the reason is that we, we acquire immunity. Because we eat pig, right? So we, we are exposing the guts to these antigens, but also other bacteria have similar antigens. So basically we, we build some sort of immunity. A way, a way to explain this is like thinking about allergy, right?

And say I am allergic to this type of food. Mm-hmm. we are, we are naturally allergic if you wish to, to some of these pig antigens that we don't express, therefore, Initially, if we'll be transplanted with a native organ, with an organ from a pig that is, hasn't been modified, we would reject it very quickly.

Okay. And so it would not help. Mm-hmm. So in time with studies that were done in baboons and other animals, we have learned which one are the main.

And so what we did was to modify the [01:13:00] genetics or the pig to abrogate the expression of these allergens. So even though we have allergy, there is no allergic response to the organ, right?

So now we use genetically modified pig to do this organ transplantation. And the experience at NYU Langone shows that they are within the first few days post transplant, which are the days in which you would hyperacute reject the organ. So we were successful in bridging that gap. Now is what next. Right.

Great . Exactly. And before I get to that big question of what next mm-hmm. , thinking about all of those changes that you've made to those organs, would that mean that people would potentially need to take less immunosuppressants or less anti-rejection medication if they received one of those pig organs?

At the moment, not, [01:14:00] and it just because long term studies in humans have never been done.

It's always long term study have always been done in baboons. Okay? BA baboons are not similar to us in terms of the medication that we give to the baboons to protect, so the immune suppression that you give to the baboons. So it's not comparable, but that's why NYU Langone and Dr. Montgomery, I started this, this program.

And we are almost the finish line for doing this study in an extended period. Mm-hmm. , because as I say before, we have bridged the hyper acute rejection. And that doesn't occur. So what we need to study now is the rejection, the long term rejection, right? Right. Now, kinda that's the thing, and that's part of my job, right?

Mm-hmm. , if we understand what [01:15:00] causes the long term rejection, we can attempt to genetically engineer pigs. So that, that mechanism would not occur anymore. So ideally in the long term, better than in humans. Mm-hmm. we, we might be able to reach a point where actually you can have a lower immune suppression and maybe, and maybe eventually a point where there is no immune suppression.

Suppression is a little bit too fast, and I wanna give you any great. Okay. It's, it's, it is a long shot, but of course, that, that, that's our, that's our intent, which actually is also the NYU Langone philosophy for human to human. Mm-hmm. The goal for us is not just that of transplanting, the goal for us is to improve the quality of life after transplants.

Right. So, e, even in human to human, the transplant, NYU Langone [01:16:00] is actively working on, on what is needed to decrease immune suppression in human to human transplants because we know that giving you an organ is only a one piece of the puzzle, right? The rest of your life should be as beautiful and as fulfilling as your life before you had your disease.

And we are very committed not forgetting that because the game here for us, it's not just the numbers, but really improving the quality of life post transplant.

Wow. That's, that's incredible to hear. Thank you for, for saying that and thinking about the, the number of people who are waiting right now for transplants around the world, it, it feels like that wait list continues to grow . How could pig organs support a more equitable system to allow more patients to, to get [01:17:00] transplants and, and more people to get off of that wait list.

That's very good point, Candice. Thank you. So it's gonna be our phased transition, right? Of course. It's everything. We need to be cautious, right? This is a very exciting moment, but we need to be, we need to be with our feet firm on the ground. Yes. And make sure that we approach these the right way. Mm-hmm. the best way for the patient. So I, I'm envisioning. The, the initial step is going to be for those that are the most disadvantaged mm-hmm. in the wait list. And so I'm talking about this very highly broadly sensitized patient with a CPR of a hundred percent that have been sitting in the well list for 15, 20 years and they are getting no offers and they're running out of option for dialysis and they are their risk in their life. Mm-hmm. .So I think that's one of the best approach. [01:18:00] You might say, Whoa. But there is a lot of antibody, there's a lot of allergy. Now, one of the study that we have done here in NYU Langone, was to determine whether indeed, There is some sort of cross reactivity with the allergy, the antibody that show against the human organs and the allergy reactivity against the pig organs and it doesn't seems to be the case.

So we believe that actually for these type of patients are very early highly sensitizer or getting any offer, running out of option, the pig xenotransplant might be the only option for these, these patients. So I see the future as studying from there and as we get better at it, right? Because again, don't forget, it's not just question of putting an organ inside, right?

Can we make this person life better? Right? If that is the case, and we can prove indeed that that works. I assume that the system is gonna start widening [01:19:00] up, right? Mm-hmm. and going down the list mm-hmm. to, to the patients that are less sensitized, and of course, yes. I mean, my, my hope and my

vision is that maybe one day anybody can be offered either possibilities, right? Mm-hmm. . Mm-hmm. . Yeah. What do you want? Right?

Yeah. I, I think that's our, our, all of our ultimate goal, right? We always think about our, our pie in the sky mission to end, Right? the waitlist list, right? And I, Yeah. Yeah. That will be, Can you imagine? Can you imagine if, if, and maybe, maybe I'm not like enough to, to see that in my lifetime.

Mm-hmm. , but I'm like enough that I've started, I was part of this, this, this wave, but can't imagine a day in which there, there is no, there is no kidney disease out there because we can at least bridge it. At least bridge it between you having a human organ with pigs. But the, the, the [01:20:00] idea is going toward the fact that we have to make those organs safe.

Yes. And, and, and, and then give anybody the option to choose. Based on what they want. You know what I mean? But yeah, that would be a, That would be a dream. True. Yeah. It really would. Yeah.

For people who want to read more about your research or read more about NYU Langone, where could they find information?

Yes. NYU Langone. [nyulangone.org](http://nyulangone.org). It's very, it's very, it's very simple to find, you find NYU Langone and then you can go to the Transplant Institute page, Subpage, and there you're gonna find a Dr. Robert Montgomery, which is our leader. And Dr. Montgomery, fun fact is not only a very incredible surgeon and [01:21:00] pioneering on many, many things in kidney surgery, in kidney transplantation. He, he was the, the first person that he, I mean, he invented a domino chain many, many years ago and the laparoscopic procedure, but so he is been, it's actually, it's actually a patient itself.

Dr. Montgomery has received heart transplants years ago, so Dr. Montgomery has been advocating for the longest time about quality of life and better transplant for everyone. So you will find the information right there. And NYU Langone is a very active LinkedIn page where they are posting all these news vaccine transplantation.

So I wanna follow, so, Other than that, you can always reach out to one of us in the Transplant Institute and we can provide you papers, literature, and any other connection that you need.

Amazing. That's fantastic. I think people will be very interested to, to read more and learn more. And [01:22:00] it's always great also to hear that not only has

somebody benefited from a, a transplant in their own life, but then they're, they're turning around and taking that personal experience to improve the lives of other people.

So that's, Candice is important. Yeah. It's important that we work on this together. Mm-hmm. we, we, for the longest time, I feel we, we kind of worked in silence, the medical and the patient donor community. We need to work together because we, we teach each other how to make the future better. Your experience is important to us because my shape up the way we do transplantation in the future, if we don't connect, we will never know and we cannot improve.

But improvement, this is the only way forward. Mm-hmm. , we know how to do a transplant. Right? The, the improvement is how to make it [01:23:00] better, how to make it last longer, how to reduce immunosuppression, how to make patient's life really, really better after transplant. That's the mission. Mm-hmm. .

That's the best possible mission we can hear from, from your side of the table as well.

So thank you so much. I'm wondering if there's anything else that you want to share with our Living Transplant podcast listeners before we head out.

Yeah. First of all, I wanna thank all the donors and all the living donors, all the families of the disease donors. You all are fantastic people. They think about it Candice, in the moment of the most and the deepest sorrow you find yourself.

That, that moment of clarity to say, I, I wanna donate the organ of my loved one and one, one single donor, one single patient, one single [01:24:00] donor can save five to more lives. Significant. All these living donors that that one morning wake up and say, You know what? I have two kidneys. I don't need that. I can give up one and save somebody else.

Thank you so much. We talk a lot about patients and, and it is important in my field to talk about patient and, and patient life and, and improving and doing better. But we cannot forget the, the donor side. And so I just wanna say we are in this together. Talk to your clinician. Ask questions, express your concerns.

There is no question that is, is, is not the right question. If you have something, if you're concern about, if you wanna know more, ask away. We are here on a mission to make sure that you have [01:25:00] the same opportunity that I have.

Right? So ask away and, and we're in this together and together we'll do great things, I'm sure.

Thank you so much. Massimo. Your, your passion comes through. And we're really grateful as patients and families and donors to know that we have people like you on our side. So thank you for all of the work that you do, and thank you so much for sharing all of that work because it's, it's not just fascinating, but it's also hopeful for all of us to think about what could be in the future.

So thank you so much for joining. Thank you for, And for everything. Thank you. Yes, thank you for me. Thank you for everything else that I learned through this experience. Thank you.

**Candice Coghlan:** Thank you so much for joining us for a special episode of Behind the Scenes at the Banff CST Conference. Please like, share, and subscribe to Living Transplant Podcast. If you have any ideas for episode content, we would love to hear from you. [01:26:00] Please reach out to us at [livingorgandonation@uhn.ca](mailto:livingorgandonation@uhn.ca). We hope you enjoyed today and I wonder what kind of tree these guests would be.

Hmm..