

Team Delfina, A Fresh Start

Delfina: [00:00:00] There's always gonna be somebody out there that will help you, and help you feel better.

Matthew: If you are diagnosed with something, never give up because something always might just happen out of nowhere.

Opening

Candice: 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 Centre for Living Organ 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 of transplant.

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 [00:01:00] seen it before.

Introductions

Sick Kids Episode: Welcome back to the Living Transplant Podcast. Today I'm joined by the Budziak crew. And mother Betsy is a living donor to her daughter, who is here with this us, Delfina. And they're gonna bring me along their family's transplant journey.

Later we'll be joined by Dr. Vicky Ng, the Medical Director and Pediatric Liver Transplantation and Regenerative Medicine Centre at Sick Kids Hospital. Thank you so much for joining me, everybody, and for co-hosting this episode with me.

Betsy: Thank you so much, Candice, for having us and for thinking of us. We love to share Delfina's journey. As you said, obviously I'm Betsy. Delfina,

she's the hero of the hour for all of us, all the time. Peter and I also have my son Matthew here as well, who is definitely part of the journey.

Candice: Amazing. So I'm gonna start with you, Matthew. Can you introduce [00:02:00] yourself and tell me a little bit about some of your favourite things to do?

Matthew: So my name is Matthew. I love to play baseball and on Saturdays I play soccer. And my favorite position in soccer is net.

Candice: Cool. That's awesome. And what about you, Delfina?

Delfina: My name is Delfina and I love my family. I love baseball, and I love soccer.

Candice: Soccer. That's awesome.

Delfina: My favorite position in soccer is defense.

Candice: Defense. That's pretty cool. And I'm wondering, Mom and Dad, can you tell us a little bit about yourselves and about your family?

Peter: I'm obviously Matthew and Delfina's father. I am the, the figurehead of the crew here. In, in name only, not, not in practice. I love my kids. We love spending time together. We do almost everything together. Somehow we figure out how to do it, but, but we, we get through it. And you know, we, we definitely enjoy each other's company a lot. Right? Yeah.

Candice: And yourself Mom?

Betsy: My name is [00:03:00] Betsy. As Peter said, we're very, very close knit family. We do try to do everything and everything together, you know, from sports, which is a huge part of our lives, to even grocery shopping. So we're very fortunate that we, for the most part get along. Obviously we have our battles. But truly, what I call us is like the four pillars.

You know, even without one it, it doesn't work. So I think that the, the best way to describe me is very family oriented. For me, family is definitely above everything else. So our passions, as I said, and I, I'm sure you got the same theme amongst all four answers is just family and sports is a close second.

Candice: Thank you.

So Delfina we'll, we'll chat a little bit with Mom about how we got to where we are today, but can you tell me a little bit about what it was like to see that mural of all of [00:04:00] those people showing their scars?

Delfina: I felt like happy to see other people seeing what I'm going through.

Candice: Yeah, it's pretty cool right? Yeah, it was awesome to get to see your picture that you took in front of that mural, showing your scar too.

So what is it like being a kid with a transplant? What do you think about that?

Delfina: It feels not weird, just rare.

Candice: Yeah.

Delfina: Like, yeah. A kid going through a transplant, like just a transplant is rare. And imagine being a kid.

Candice: Mm-hmm.

Yeah. That's tough stuff. Mm. You're super brave and super strong. Mm-hmm.

Yeah. And what about Matthew? What is it like to be a brother to a little sister with a transplant?

Matthew: Well, I loved her and I hate, I hated seeing her going through that.

So I love to visit her every Saturday. [00:05:00] And every time I came there, she would smile the second I walked in. I hugged her and I kissed her.

We always used to play in the crib.

Betsy: You remember that? You probably don't, but yeah, he's right. He used to play with you at the, at the kids at crib, but Sick Kids crib.

Matthew: If you're a sibling that has another sibling with a bad condition, just always visit them once in a while and cheer them up and play with them. And it'll always make them smile cause then it makes them feel more, it makes them

feel better. Like, more better than they were before just sitting in the crib. Sad and sick.

Candice: So you're pretty protective, big brother then?

Matthew: Yeah, especially when it, it comes to bullying. Yeah.

Candice: Yeah, for sure. At school. She's pretty lucky to have a big brother like you.

Matthew: Thank you.

Candice: And what about you Delfina? If there's other kids out there who are going through some illness or if they have [00:06:00] a transplant, what would you tell them?

Delfina: Like don't worry. There's always gonna be somebody out there that will help you, and help you feel better.

Matthew: If you are diagnosed with something, never give up because something always might just happen out of nowhere.

Candice: That's so sweet Matthew. You guys are a very amazing family together.

So, Betsy, I'm wondering if you can bring me back a few years ago and let me know, what was that journey like before diagnosis?

Diagnosis

Betsy: So basically going back, and it's timely because it was to this exact week where we first visited Sick Kids. And going back even further when Delfina was born, she was born with jaundice. So we stayed at the hospital longer than we did with Matthew. And they did, you know, the typical under the light and monitor her.

And she was discharged two days after [00:07:00] birth because they said they were satisfied with how she reacted to the UV light. At the time, obviously we were completely oblivious to the fact that there was two types of jaundice. That was kind of the newborn jaundice, which the UV Light did help. And as we got

into her first month after birth I remember saying to my husband, like, “There’s something not right here.”

It’s different than it was with Matthew. She just wasn’t sleeping as well. She wasn’t as happy. She wasn’t satisfied after nursing. And I supplemented her with formula, which at the time I wasn’t a fan of doing. But, you know, as most mothers do, they do what they have to do for her to gain weight and get healthy.

And even that didn’t really seem to satisfy her. She still wasn’t sleeping properly. And then at her two month checkup, which was in November, eight years ago, her pediatrician noticed that her skin was [00:08:00] looking a little yellow. Her eyes. He actually had a medical student who was the first one to observe her tone, her skin tone in general being off.

They ordered immediate urine tests and blood work. Again, I was just thinking, “Oh, you know, she might have a little bug or something that some amoxicillin or more UV light would treat.” And then it was, I think like not even 24 hours later that her pediatrician had called me and said “Okay Mom, you need to pack a bag, trek down to Sick Kids because Delfina’s liver is very sick and it needs to be looked at.”

And at the time I remember just thinking, “Okay, sounds good.” You know, there was no tears, there was no fear, there was no realization of what we were in for. It was more just, “Okay, I need to pack some pajamas. We’ll head down to Sick Kids, go under a UV light and we’ll be back home within 24, 48 hours.”

And we go down to [00:09:00] Sick Kids and they did the initial diagnostics where they did additional blood work, urine, et cetera. And it wasn’t an immediate diagnosis.

They told us some of the potential conditions that she might have. And right away, I think that’s when I started realizing, “this isn’t your typical UV light.”

And that’s when I started asking the questions, “Okay, well, what does this really mean?”

Like, I think it slowly, it started becoming obvious that this was more serious than I had thought and they gave us possible conditions that it could be. And one of the last ones that they mentioned was biliary atresia, which for me, I had never heard of before in my life.

And they explained to me when it was, the procedures involved to diagnose and confirm that that is truly what Delfina had and what the treatments were, what the resolutions were. And, and then I remember just hearing [00:10:00] “transplant.” But it was after a series of, “Well, we need to do these dye, cholangiograms and blood work and urine analysis.”

At the time, kind of went in one ear, almost out the other. I just heard the takeaway was a transplant. So ignorant, silly Mom asked the question, “Okay, well can we just fast forward all these other tests and just get to transplant?” And I remember saying to the doctors, and remember saying to my husband and my family, “I just wanna skip this, I wanna fast forward. I know she needs a transplant. I know that’s what she needs. Can we skip it?”

And unfortunately that’s not the practice. So she did have her first surgery just shy of two months. And it was the Kasai procedure, which they explained to us was a makeshift drainage for her condition because biliary atresia explained to me was the malformation or lack of bile ducts flowing from the liver to excrete [00:11:00] like the normal human anatomy.

Mm-hmm. So they did the Kasai and they did tell us that it was a bit of a long shot just because she was really close to the two month mark and the way they explained to me is the earlier in infancy that they can catch it, the better. And she was really almost at the high end of two months.

Mm-hmm.

But obviously, you know, we were still hopeful for the surgery. And I think like, maybe not even a day after her first surgery, which was Kasai and they explained to us that, you know, “It, it wasn’t a failure per se, but it wasn’t a success,” because the bile drainage and flow that they wanted to see wasn’t there.

And it became apparent after her Kasai because we were in and outta Sick Kids for a long time after that. Simply because she kept getting recurring liver infections and having to be in hospital on site, getting antibiotics for minimum of two [00:12:00] weeks. And it was almost like with each recurring infection, it was taking a further toll on her.

And the antibiotics were not as effective. And, and as time progressed, her liver was becoming increasingly, increasingly scarred, which made her more swollen, especially her abdomen. So it was kind of tough to go from, “Okay, no problem.

We'll go to Sick Kids under a light for 24 hours," to seeing her worsen and not getting to where, you know, in my mind, was the transplant, the endpoint.

It was almost like, "Okay, we did it your way. We tried the Kasai that failed, we're putting on antibiotics and it seems to, be a band aid solution. Can you listen to Dr. Betsy now? Can we just get to the transplant?"

The first part of her journey was just learning that A, she was born with the liver condition. And B, being diagnosed with the biliary atresia.

In the background all the while, [00:13:00] which obviously as a mother, the focus is always on your child. I was also diagnosed with postpartum depression coupled with post-traumatic syndrome just because as I said, even before she was diagnosed, she was not sleeping, she was not eating. She was constantly crying. And it made me feel, I think as like a failure of a mother. So it wasn't easy for any mother to have to go through learning your child was born with a, a condition of disease, but more so when you're already in a mental fragile state.

So I think that is probably, we can say was the hardest two months of our lives from when she was born in September to being diagnosed in November.

Candice: So you're at the two month mark when those antibiotics weren't working, what was the next step for you guys?

Betsy: I actually just believe it or not, felt almost relief after her diagnosis because [00:14:00] it was one of those moments where I was like, you know, reassured I was right.

I knew something was wrong, I knew something was off. And also relief from a mental standpoint because Sick Kids had become our home away from home. That's where I spent my maternity leave. And I didn't feel alone. Where at home it was just baby and I. Peter was at work, Matthew was at daycare, and the home had almost become my prison where I was feeling like a failing mother.

And now I was at this world class facility where everybody was a smiling face, a hopeful face, and a place where I knew I wasn't alone. Even if it meant just being able to go step away from a crying baby for a cup of coffee.

Mm-hmm.

It was actually the opposite when we were discharged. Normally that's a happy occasion, you're going home.

It [00:15:00] was fear on my part where, "Oh my goodness, I'm going back to my prison. I'm going back to where I don't have help. I don't have hands. I don't have medical professionals that might be more capable of taking care of my child than myself." So it was a rollercoaster of emotions. And that was above and beyond just the fear of, "Is my child going to make it even to transplant?"

Because as I said, we did see the deterioration happen. And so I think just to describe it best would just be a rollercoaster of the unknown fear, despair almost of, of a mother not feeling able to protect and help her child.

Candice: And Betsy, once you got that diagnosis were you able to also get support for yourself through this journey?

Betsy: Absolutely.[00:16:00] Delfina's pediatrician did notice on that same day every two, two month checkup that visibly, I wasn't myself, and he actually is the one who suggested that I should get myself checked out.

And after Delfina was admitted to hospital. We had a fantastic family support system that I was able to look after myself. And I did get diagnosed myself and I did go on medications. It was definitely a very tough journey. But we had probably the best resources with Sick Kids and our family that I was able to get through it. And everyone asked at the time, you know, "How do you guys do that?"

"Oh my goodness, we couldn't do it. If it was our child, we couldn't do it." We would've said the same thing in the other person's shoes. But when you are in it and you are the parents, you do it because there's no other choice not to. So I [00:17:00] think we were, I was very lucky with all the support I had around me to get through it. And obviously Delfina to get through it as well.

Peter: I think that's a common misconception is that, "Oh, you know, the, the parents, they're so brave, you know?" I'd love to say that we were the most amazing and brave people, and we knew exactly what to do in every situation. Man. We were chasing our tails all the time. We had no clue what was up and down, and our heads were spinning.

You do it cause you have to do it right? They're your children and you have to take care of them. Right? And the mental health nowadays, it's turning into

such a big deal, and we're learning new things, almost on a daily basis. And it's such an overlooked aspect. Obviously Delfina is going through this, but, Betsy was going through a lot of this herself, right? Mother of a newborn. Mm-hmm.

And the father of a newborn, you kind of look inward and say," What did we do? What did we do that this happened to her?" You blame [00:18:00] yourself. Right? And you know that there's a lot of professionals out there that can help you get through those dark times and that definitely shouldn't be overlooked.

Candice: Mm-hmm.

Absolutely. Mental health is so incredibly important through anybody's journey. It doesn't have to be a journey like this, it can be for anybody. But I agree it's difficult to sometimes as parents, find the time to take care of, of yourselves, especially when you're going through something like what, what you guys went through.

Peter: Exactly. Yep.

Candice: And what, was it like for you, Peter? Having your wife and your newborn baby at the hospital in and out and, trying to keep Matthew occupied, and balancing everything as well?

Peter: So we, we kind of tackled it as a family. We have a lot of extended family as well. So they were more than willing to help [00:19:00] out. We actually had a rotation. Every time Delfina was admitted for her condition. Every time we literally had a schedule of, "Who was staying the night with Delfina?"

So it wasn't all on Betsy and myself. My family helped out. Betsy's family helped out. So Delfina was never alone for you know, longer than about 30 seconds in the hospital, as, as people would cross paths in the hallway, as one person leaving was trying to go catch the GO train to come back home.

Everybody helped out all the time. Matthew, being three years old and, and our first born, he took a backseat to it, but we tried to keep things as normal as possible for him.

So he still went to daycare and my father-in-law would pick him up a lot. And so we wanted to keep things as normal for him as, as possible in such a situation. A lot of older siblings, when their new sibling is born [00:20:00] gets very, they get very jealous and territorial. He did the exact opposite. He

embraced her from the moment. And he never was resentful towards her, that she took his parents and the two that literally doted over him for the first three years of his life, he was never resentful that she kind of took that away. And, and kind of sent his life into an upheaval.

Obviously he wasn't able to see her as normal siblings do, but he would get to the hospital and they would just rejoice in seeing each other as she, she'd have this huge smile and he would climb up into the crib with her and just show her different things that he did at daycare and just tell her and just make sure that she was okay.

And then he'd go off and do some stuff with some of the amazing nurses, and then he'd come back and play with her again [00:21:00] after her nap. And he was just such a trooper and such a terrible situation. I credit him a lot as to why we were able to make it through.

He could have easily, and nobody would've blamed him had he made that situation tougher. But he did the exact opposite. He made it so much easier.

Candice: When she was admitted, when she was in hospital, they were doing the tests and I know Betsy, you kept pushing for the transplant.

How did you guys get from the point where the doctors were trying different things to where they finally said, "Okay, this is the moment. This is the time when we agree with Dr. Mom, it's time for a transplant."

Betsy: The first admission after the initial diagnosed admission, and we did the Kasai, we went home after she had recovered from the first surgery.

And the first fever was coupled with our initial follow up clinic with Dr. Vicky Ng. [00:22:00] And we took Delfina to Sick Kids and, you know, we were anticipating, we were going in, they're doing some blood work and they see she's stable and then they'll send us on our way. We had gone to clinic, what they call clinic appointment, and they did blood work and Dr. Ng came in.

I think it was like maybe the first time we met her and we, we were anticipating the, "Yep, she's stable. You know, it's not ideal. The surgery wasn't as successful as we wanted, but she's stable enough to go home." And Dr. Ng came in. And told us, okay, she's not liking what she's seen in blood work.

And the numbers were off and that we were to stay that night. This was first thing in the morning. And Peter and I just looked at each other like, "We can't

stay the night. We didn't bring an overnight bag. Matthew's at Day's Care. You know, this is an inconvenience. No thank you."

Mm-hmm.

And we were, I think, poor Dr. Ng, I think she probably was the brunt of our frustration cause [00:23:00] we were "Really, is this necessary?" And obviously we did get admitted and at the time it was just, we were almost resentful or frustrated, like, "Why do we have to spend the night at the kids? This isn't what we planned. This isn't what we wanted."

"We just got out."

Yeah. "We just had out."

Yeah. Yeah, yeah. We felt like we just had gotten home and as, as we said, Dr. Ng ordered a two week antibiotic for Delfina, the infection in her liver. Initially the idea that we had to stay was almost like it's against our choice. But then once we, we came to terms with her being admitted we knew that it was the best thing for her.

And as you, can almost see to her turning around, her fever started to break. She was a little bit more comfortable. She was sleeping better. And then two weeks would go and then we'd be discharged. She seemed as healthy as she could be at the time. And then we'd go home and it would be, a month before the next fever broke. [00:24:00] And we almost then at that point had learned our lesson where we knew the next fever meant almost an automatic admission at Sick Kids.

So we were back at Sick Kids, for two weeks. And then we'd go home, and then, we were almost on pins and needles waiting for that next fever to come.

And when the fever came, okay, well, and at this point we were almost professionals. We had overnight bags packed at the ready at all times. Our family on rotation where we were very lucky, when we knew Delfina was getting admitted, we, we were very fortunate where we knew it wasn't the end of the world. It was an inconvenience. Yes, it would mean I would not see my son for a days at a time or Peter not seeing his son. But we knew that we weren't alone, that we had our family. We knew that she was in the best hands in the care of Sick Kids.

Each admission became a little easier because as with [00:25:00] humans, the more you do something, the more you get used to it. It became familiar. But then we started finding, “Okay, we’ll take a two week antibiotic.” And, and they would say, “Well, sorry, it’s not gonna cut it this time because it, it’s being a little bit more resistant. Her infection is a little bit more severe.” This is now three weeks.

And then we went from being home from two months at a time or a month, you know, which for us was a good interval to, two weeks, one week, three days, we are getting more and more. It seemed more that we are spending more time at Sick Kids than at home. And towards April, where, which was also Delfina’s baptism. And now I’ll never forget where the day of her baptism. We had already booked the church. We had booked the reception venue, invites were sent out. And wake up in the morning and her baptismal gown was all set up and ready for photographs.

As I approached the crib, I felt the heat coming off her crib before I touched her [00:26:00] because her fever was so severe. Her face was just like in agony. You could tell she was in absolute discomfort. And I looked up Peter and I said, “What are we going to do? The church’s book, the invites are sent. Everyone is, on their way to this baptism.”

So knowing Delfina, the warrior that she had become, we proceeded like, “let’s go to the mess. Let’s go through the ceremony.” And then afterwards, Peter, Matthew, and family and guests will head to the reception venue. Mom, Delfina would head down to Sick Kids.

At that point, as I said, we had become so close that I had them on speed dial and I’d given them a call and I said, “Okay, Delfina’s on her way, we’re coming down. She’s very fevered, she’s very uncomfortable, you know, round us up for another infection.” And at that point, the GI doctor on call, who I spoke with on the phone had told us, “Okay, Betsy, we’re prepping for you. We’re ready for you. Come on down. But just so [00:27:00] you know that this is gonna be it. This is gonna be the last time that you’re admitted before transplant. You will not be going home until Delfina has been transplanted.”

Definitely mixed emotions of, “Yes, this is what I wanted. This is what I was waiting for.” To, “Oh my goodness, my baby is going under the knife for a major surgery.”

You know, it’s not like they had a liver waiting for her that day. So we knew we had gone to the beginning of the end and the for transplant journey where I

knew she was getting transplanted, but we still didn't know. Did that mean in one week, two week, two months?

Again, you live it, you learn. We had become familiar with the transplant team and they explained it to us that the standard of care in Ontario was a deceased donor. So then I felt like the worst person in the world thinking, "Does that [00:28:00] mean I have to wait for a baby of her size and her blood type to sacrifice their life so that Delfina can get her liver?"

Thrilled to become educated that, no, not necessarily because you can be a living donor. And again, going back to the standard of care, because the first thing that I heard is "living donor." "Okay. Like, sign us up. Sign us up."

And that's when Peter was like, "Okay, Betsy, it can't be you because you're still on your mat leave.

You're taking care of Delfina on a day to day. You still have a three year old to take care of. It can't be you. It'll be me." And almost immediately Peter was ruled out because he wasn't the same blood type as Delfina. And then my brother at the time who was single, still no children of his own, said "it makes sense for me." And he was thrilled and excited to, to be the one at that point, it was basically a fight between Peter and my [00:29:00] brother, my sister, both my sister-in-laws of "We wanna be the donor, we wanna be the donor."

Again, living through the experience ourselves. We found out that in, in Ontario and through the program at Sick Kids and, and Toronto General, that they only will focus on one candidate at a time. It's not like, you know, their lineup was exclusively for Delfina. So the focus went to my brother and he'd gone through the blood work, the ultrasounds, the MRIs, and he was super hopeful cause he had almost gotten to the finish line of being selected.

But one of his last blood works, there was a number that the doctors weren't satisfied with, that then eliminated my brother as a viable candidate. And I remember it was one of the first times I've ever heard my brother swear in his life where he was angry with himself, angry with the world, frustrated, sad.

But, you know, I became into that [00:30:00] maternal role to my brother. Like, "Its okay. It wasn't meant to be you. It, it just means that, you know, we're gonna find someone else."

And so then my sister stepped up and she had a daughter of her own, my niece. And, you know, we all thought my sister's gonna be selected. She's the epitome

of health to this day. She takes care of herself. She works out. We like “It’s gonna be.”

Same thing. I don’t know the exact name of what they found in her liver. And it wasn’t harmful to my sister, but they said “It’s not the ideal where they don’t wanna take the chance that if it becomes something later on in Delfina.”

So then my sister was select x-ed off the list and at this point we started looking at each other like, “Wow, this is gonna be harder than we thought. We thought once living donor was an option, it would be a walk in the park.” But at this time now it was Peter was striked out. My, my brother was stroked out as an option, and now my sister, so next up was my sister-in-law and Peter’s [00:31:00] sister was also ruled out.

And then at this point I think Peter was when he was like, “Betsy, this might not be as easy as we thought. We might need some support and some help.” And Peter made the decision to make a plea on social media.

Betsy got tested shortly after I was turned down and they, believe it or not, they found what was going to develop into cancer. Nodules on her, on her liver that was going to turn into cancer later in life. So they said, “No, no, we are not, this obviously isn’t gonna work. Let’s move on. Who’s next in line?” And the good thing is about that is they were actually able to burn off the, these potentially cancerous nodules and probably save her life.

I mean, depending on when and if this was caught. So in, in some really weird kind of [00:32:00] warped manner, this whole, you know, this whole situation probably ended up saving Betsy’s life. And she was ruled out and then, we went down the line and ruled out, ruled out, and ruled out.

And after my sister-in-law was ruled out, I put my head in my hands and I was already having enough, dealing with enough inside, not being able to help my daughter, not being able to save her as I wanted to.

The former owner of the Ottawa Senators, Eugene Melnyk, was back at the time, was recently in the news with a public plea for help with a living liver donor. And he was able to get a lot of, a lot of people to step forward and offer their help.

My idea was I was gonna ask a few of my cousins, but I didn’t wanna make it awkward to ask them. So I just put a plea on social media, on my Facebook

page. [00:33:00] With the hope that my cousins would reply to, “Hey, we’ll get tested.”

And just kind of replenishing the, the line of people that would, you know, get tested and get worked up so that they might, they could be a potential donor. It went viral, literally overnight. I clicked post and put my phone down and said, “all right, go to sleep.” I woke up to what?

I’m fairly certain, I still haven’t caught up to it this day was the amount of replies and responses.

One person in particular who was in charge of media relations for a political party, got in touch with me. She had also worked on the, the Eugene Melnyk stuff. So she offered to help and she got our word out there in a manner that, there’s no, I could have done tried for a year and not done it. She got it out.

She set up a Gmail account with a bunch of information. And then all [00:34:00] the Ottawa Senators, tweeted it out. We started getting a ridiculous amount of news outlets and people just stepping forward to sharing our story.

I also worked for a media company. They put it out there, major Canadian media company. They put it out there, everywhere. When Betsy got turned down, my sister-in-law got turned out, probably the lowest point of my life, and then almost 12 hours later to wake up to all of this, it kind of renewed my faith in humanity and in life. And it was just this moment of sheer realization where you just look and say, “This is, this is how good people can be. This is how good society can be when we take care of each other, right?” When we’re, when we’re there for each other.” And it was just an absolutely awesome moment and one that I’ll never forget for the rest of my life. It’s just so nice to see that there’s all these strangers who are willing to help the people that you [00:35:00] love most.

Peter: We were getting tons of interest. Our story was being shared everywhere at one point. I think that 1100 people had offered to help Delfina and we were completely floored. I couldn’t believe how many people said. There was people in different countries.

The military armed forces just, it was just phenomenal. And the amount of people that helped, even people that didn’t, would just share our story. And throughout all this Toronto General at the time was extremely understanding and they were working everybody the best they could and trying to facilitate everything.

And the doctors came back to Betsy and said, “I think we can, burn off the cancerous nodules on your liver. And I think that might make your liver [00:36:00] transplantable.” And this is while this whole media blitz for Delfina is going on, and I’m like, “Oh my God. We have upwards of 1100 people who are trying to help Delfina, and now it might end up being Betsy again.”

We were obviously very conscious about all the people we had met at Sick Kids. All the other, amazing kids that we met where they needed liver transplants. So we started trying to help them as well.

And meanwhile, Betsy undergoes the, ablation, right? And it was successful. We had to wait a few weeks to see if it grew back or anything like that. Nothing grew back and the doctors decided that she could be the donor, and it was it was ama, it was a great feeling because kind of what we wanted from the beginning ended up happening. Everything just kicked into high gear and went into fast forward, and it was kind of like a blur where we got ready, everybody [00:37:00] got ready.

And, the whole time in the hospital, Delfina’s trying to gain as much weight as she possibly could. She’s waiting for this transplant and she has to meet all these, these goals. Feeding goals. And the, the formula is a high calorie formula and oh my God. Like we tasted it. I can’t believe that she was able, that every day they would set a new goal for her and she would surpass that goal somehow.

Her tummy would be, distended and, like there was so many different times where, PICC line, she would get a PICC line and that would come out.

And just so many different little hurdles and hiccups and through the whole thing, she’s just a normal baby. She’s learning to roll over in the crib, even though she has a descended belly.

Towards the transplant, she started grabbing the top bar of the crib and pulling yourself up and learning how to, teaching yourself how to stand.

And the nurses turned to us and said, “We’ve never seen a [00:38:00] child this age, this condition doing these things.” And I mean, we should have known at the time, right, what kind of kids she was going to be. But to speak to the transplant, the day of the transplant came and I had my son with my father-in-law. And Betsy was obviously at Toronto General getting ready.

And I was, myself and my sister-in-law, my mother-in-law were with Delfina. I'll never forget the moment where, I was, there was this excitement in me, but this nervous excitement where I'm holding her in my arms and the nurse comes over and says, "Okay, we have to take her to prep her for the transplant. You won't see her again until after the transplant. I said, give me another second, please."

I walked off into the corner and I just completely started crying. Apologizing to her for everything that she had to go through and that I promised that I was gonna be there for her and that we were going to get our lives together and get moving.

I couldn't help but thinking, you get this [00:39:00] creepy thought in the back of your head, like, "Maybe this is the last time I ever hand her over." And I couldn't shake that feeling. And once I did, and they walked away and I collected myself, and a calm kind of came over me and we're in the waiting room and with my in-laws and, kept getting updates.

The staff was amazing about giving us updates, not only about Delfina, but obviously about Betsy as well. And it was, towards the end of the night, everything had been successful and I got to see her. She was in such discomfort, it was hard to watch. All these tubes are sticking out. Everything is.

And the next few days were really, were very tough because she was in a lot of discomfort and we couldn't really pick her up. She was dying to just be held and you know, be cuddled a little bit. And we couldn't do that because of everything that was sticking out of her.

And we didn't want to, disrupt anything. [00:40:00] And finally, one morning I walked in and she just looked at me and she wasn't crying and she wasn't upset. She just looked at me and she's like, "Okay, we got this. Like, we're good now."

And honestly, from that point on, there, like the, there has been almost no hiccups whatsoever. And it was, honestly, it was like she took Betsy's liver and just said, "You know what, mama? Thanks. That's all I needed. All I needed was this, this piece that wasn't working. You gave me this piece. We're good. Let's go. Let's go now."

And we always like to say that, "Yeah, Betsy 100%, saved Delfina's life." There's no question about that. But Delfina also saved Betsy's life because, in this weird fashion, without her condition, Betsy never would've gotten worked

up and they never would've checked her liver and, who knows what would've happened in two [00:41:00] years or in four years, or in six years, right?

It's this funny way of how these things work out. We say we, "They, they saved each other's life." It's amazing.

Betsy: Yeah. I remember Peter saying that in the ICU, obviously I didn't get to see Delfina immediately on these in the ICU because I was in my own ICU. And I do remember finally, I think it was the day after surgery and I was trying to get up and, told the staff at Toronto General, "I wanna go see her, I wanna go see her."

And they said, "You can't. Like, you cannot, you're not allowed to move yet. You need to wait at least until tomorrow." Obviously, there wasn't anywhere I could fight them off. I was literally immobile. So, I had to listen. And the next day when I finally did. And it was just, it was so surreal because I remember being in a wheelchair, cause I've never really been one in my life.

There's a tunnel that connects the two hospitals going through. And I was just exploring like, "What a world this is fantastic." You know, the service [00:42:00] and excitement, just excitement like, it was, it was a feeling that I'll never, you can never describe it just like, it felt like the longest journey ever. Cause I just wanted to get to her. And then when I finally did, and as Peter said, it was a sight to see a little shocking because, you could actually still see the, the wound and the bandages and the wraps and obviously she was still swollen from the surgery and from her. The swelling, even going into surgery is, as we said, the infections that caused her abdomen to swell.

So she just looked very swollen, very weak, but still, like, she managed to open her eyes and just give each other a look. And I remember I'm holding her hand and I told her "I knew this was all that you needed. I knew it. I knew it from the day we first arrived at Sy. And now you got it. And now you're just, there's no looking back." And there really, really wasn't. And then even in the ICU, I went back and then Peter told me later that when he had gotten back to the ICU, they had like strapped her down in the ICU.

She was [00:43:00] strapped down, and then he was told by the staff there, they had to strap her down because she was trying to pull at her wires and pick and stuff. And it was just, it was just not normal because she should basically have been sedated and not even being able to move. But she has such a ferocity in her that she was like, "I don't need this ICU. I don't, you don't pamper me. I just, I wanna get going. I wanna move on. I wanna heal and get over."

And, and I remember them telling us that they could take up to two months for her to recover from surgery. And she did it in two and a half weeks. And that was amazing. I think you were out in what, three days? Yeah, three days. She, Betsy, came out of the hospital, came home and cooked two meals, and did like the dishes. Dishes, yeah. And then, and put Matthew to bed. And I'm like, "What is what?"

Like I get a, I get a sniffle and I'm done. And you just went transplant surgery and you donated a part of your organ and you just cooked two meals and it was, it was awesome.

Candice: My mom was my donor as well, [00:44:00] and I always say that my Mom gave me life twice. And now becoming a Mom myself I, I couldn't imagine what the two of you have been through. Is one of the things that kept you going through this whole journey? And to that end point of, "I am getting out of this room and I am seeing my baby girl and making sure that that liver of mine is working in her."

Betsy: So I think I said earlier how everyone applauded how Peter and I had gone through it. And, you know, how did we, and, and what I told everyone, and it wasn't anything magical or anything, but it was Delfina day in, day out.

The strength, the perseverance, she had it, she made it easier for me. Her determination, her smile, her resilience, it inspired me to, to [00:45:00] have the same, to go through the same. And that was even just before I was considered to be a donor and forget about the physical trauma that it caused, obviously to myself.

But even just mentally, to be honest, I think the mental journey was much harder than the physical journey. And I remember during the workup, the team saying, "This is a major surgery. This is definitely a major surgery. You are, your body's gonna be, feel like you were hit by a truck."

And I think that was literally the analogy they used. And obviously, who wants to get that feeling, but I truly don't to this day do not remember any pain. I was never in pain. Obviously the pain medications speak volumes of that, but there was never a time where even after I was off the painkillers that I felt any pain.

It was all I felt was Delfina's smile. All I saw was her getting better every day. Getting healthier, getting stronger, getting better. [00:46:00] So there was no, she made it easy. There was no like, "How did you get through the journey?" By her smiles? By her smiles, her strength, her resilience.

Sick Kids Episode: I've told her this daily, there's not a day that has gone by since the surgery that she doesn't do something even smaller big to inspire me.

And I tell her every day, you are my real life superhero. You are my real life superhero. You're the strongest thing I've ever seen. And she makes us all aspire to be. Just hold a candle anywhere to her cause it'll never try to pass her. It'll never happen. She's the clear front runner of hero.

Betsy: But just to get to that level. So how did we get through it, from her? We, we followed her lead. That, that's how I did.

Candice: I think some of the unsung heroes of all of our transplant journeys, of course, are our family members and all of those people who support us along the way. And just listening to you guys [00:47:00] about how close you are as a family and what you went through with Matthew being so young, but still supporting his sister, anytime he could, what do you think could be done for siblings or, or even family members who are going through these journeys themselves?

Peter: For families to just realize that "Yes, you obviously have a child that is sick, but not to forget about the other one." We really tried to make it a point with Matthew, so that he didn't feel left out that his world was already turned upside down, but we still wanted there to be some stability.

Betsy and I are extremely fortunate to have my family and her family. We're close with them as well, and they bent over backwards to help us out. So we were able to provide that for Matthew, right? Where, one of us wasn't always in the hospital.

So we [00:48:00] were able to give Matthew his own time, right? He was able to still have his parents present and with him, but still at such a young age, he understood the gravity of kind of what was going on.

And he was sympathetic which is phenomenal for a three year old to understand that. He would just do things like if the nurse put a needle in her to take blood and she would cry, he would yell at the nurse. So he felt, making him a part of the journey and not just by yeah, bystander or just watching the journey.

He was part of it with us. He took those steps. He felt those feelings. So he went through it too. And I, I think just involving him in everything and, within reason obviously, but just keeping him with us and giving, showing him that he's still there and he still loved and, we still remember him and everything like that.

Betsy: And then me just kind of reiterating what Peter said too is with Matthew being so young, he was three when [00:49:00] she was first diagnosed, but we kept Matthew involved. I think that's kind of a key thing to say to other families and siblings was having him because he understood that Delfina was born different than him.

He understood that Delfina had more vulnerabilities than he did, and he became like a tertiary caregiver. And at the time, at three years old, that might have been something as simple as, "Help Mommy feed her, hold the bottle for her." She'd love if you feed her. So he would feed her from the bottle sitting in the crib with her, again at three years old. That's how he contributed. He played with her, he made her laugh. He made her forget that she was at Sick Kids. And she was just a little sister playing with her brother. Fast forward now they're a little bit older, Matthew's still given that role of you're part of her caregivers.

When you go to school and you're questioned of "Why are you still wearing a mask?"

"No one is wearing masks not mandatory anymore."

"Why [00:50:00] I do it, is for my sister, my little sister, she could get sick. And if I catch something, I might just miss a week of school. She catches something, it's a hospital visitor or a hospital stay." And so and he explains that and he almost wears it as a badge of honor.

He's almost excited for someone to ask, "Why are you still wearing a mask? Why are you wearing a green ribbon? Why does Green Shirt Day mean so much to, to your family?" Because, we campaign for that, even at the school level. So just having Matthew not be just a sibling, but he's a sibling and a caregiver to his little sister.

So I think that would be the advice, is just involve them. Don't put them as a bystander. Make them aware. Educate them. Obviously at an age applicable level as to what they can do to support their sibling.

Candice: Post-transplant, what changed for your family once you were all back home and you felt like you were healed [00:51:00] and ready to move on to what was next?

Betsy: So, I mentioned at the beginning when Delfina was first diagnosed, we were actually in a different home than we are now. And coupled with her being so ill and me unbeknownst to her illness at the time, my postpartum, being alone

with, a crying, a newborn all day long, the home had become my prison. Where I dreaded going home to that.

So fast forward to when Delfina was discharged. I know Peter was saying, or people will say “You’re a normal family again.” I don’t think we are a normal family. I think we were even blessed to be not a normal family where we weren’t just healthy and happy, but we are healthy and healthy and not taking for granted what the normal family would your everyday health.

I say that after when Delfina was discharged, she would smile at like the seagulls and the pigeons outside of the hospital. Everything for her was a new experience. She just took delight in everyday, [00:52:00] mundane things. And again, I tried to take her lead where not take things for granted, really understand that life is short, tomorrow’s not promised.

From when I was a little girl, I always dreamed of having a house with a pool, and I think when Delfina was discharged, it kind of drove us to push for, “Let’s find that dream home, let’s find that house with the pool. Let’s change the scenery. Fresh start all around.”

So we were thrilled to actually be discharged for, for good. Delfina’s never been admitted back to Sick Kids since then, other than for a, biopsy, which always ended up coming in the clear.

Where we finally felt we can now be the foursome. It doesn’t have to be “Whose night is it?” “Am I with Matthew?” “Are you with Matthew?” “No, we’re, it’s the four of us.”

And it might be, going back to how we started it as to why I love to this day, whether it’s going to a baseball game, or doing grocery shopping, [00:53:00] or shopping for back to school clothes. I want to be the four of us. It’s the four of us. We’re the four pillars. And we wanna enjoy every single moment of what now is a, a very healthy and thriving life for the four of us.

One of us is down, the four of us are down, or the other ones are there to pick up. So I think we are just finally excited to, to be back home together and not have to feel like it’s, choosing which child is with who and which parent is with who we’re, it’s the foursome, all of us.

We just were very thrilled, excited, grateful, and very blessed to be able to enjoy life together.

Peter: I think that biggest change was, the house. It was a very rough time in the first nine months, of her life. We went through some very low moments and we saw each other at our, probably at our worst. Right? And, we loved that house because Matthew was born into that house and right? That was the first home we, he slept in and everything like that. But it had become a home where there was some, negative [00:54:00] memories, right? And her room, which before everything took a turn for the better, it was almost this place that you didn't want to go into because the negative feelings that were involved in that room. And, I'm a firm believer of like, the energy and you put out positive and you take out, you take back the positive and, and that sort. And her room is just such a negative kind of space.

“We need a change. We need a change for the betterment of this family and to create a brand new bunch of brand new memories in a place. And so we moved to, a dream house.” I think that was a really big turning point because we felt like not only did we get a fresh start with Delfina's liver, but we got a fresh start in our family dynamic, right?

We got to get away from those negative memories and those negative feelings that were associated with her room. Or certain instances where you'd look at something on the floor and that would remind you of something. You're away [00:55:00] from that now and you get to start brand new in a fresh start.

And it also helps that Delfina is one of the most positive people you'll ever meet. It's raining outside, she's happy. All the grass and the trees are getting fed. And then it's sunny and it's great because we can go out and do whatever we want, right? I think we have kind of been forced to adopt that.

We're very sarcastic people, but we've been forced to adopt that way of thinking as well because of her. She's made our lives better, like so much better.

Candice: Do you have any advice for parents who are going through similar journeys at Sick Kids?

Betsy: Sick Kids has a great program that at the time, pre pandemic was like Coffee Parent Hour. That's basically where I met all the families that I'm still in touch with to this day.

I think it's a very crucial thing for humans to know that they're not alone, that they're not going through something [00:56:00] by themselves that there's hope.

It's not just about sharing success stories, it's also about sharing the heartaches and crying on each other's shoulder. And it's okay to feel that, not every day is rainbows and, everything just is perfect. So I think you, it's important to have someone that is going through a similar journey as you, but also being able to relay those feelings.

Because as I said, it's fantastic that I had the family support system and they were all great and we did go through it together, but none of them had a child that was admitted at Sick Kids. These ones did. And also just the staff at Sick Kids. You can see with Dr. Ng. It wasn't just a patient doctor relationship, it was, a relationship where, where it's almost like a personal friend that you're speaking with. So just to the families that feel hopeless and alone. And [00:57:00] "Who do I go to?" Like, break out a little bit. I know its difficult now. It's, not every hospital is worth the restrictions in place, but, the beauty of the virtual world is there. Reach out to those programs, find those groups, open up, and also yourself be a shoulder to cry. And Dr. Ng has reached out to Peter and I and said, "Would you be okay if we put another family in touch with you?"

"Absolutely. It would be an honor and a pleasure to have them come to us. Ask their questions, ask about anything. Even if it's something as ridiculous, 'How's the food at the food court at the hospital?' That's okay." Everything and anything is not off the table. I think just making sure that you have a great support system and whether that's blood, family, your physicians, the staff, or fellow other families and patients, just don't go through it alone.

Use the supports that are there that are offered and sometimes seeking them out yourself. They might not be offered to you. Go find them, but [00:58:00] just don't go through it alone.

Candice: Is there anything that we missed that you think we need to include?

Betsy: Just my medal. Just, this is what Delfina and I have, it's, it's actually in lives in Delfina's room because it was award to me, but I like basically give it back to her. So it's one of our Gift of Life, right, Delfina?

Yeah.

So the first time they gave it to me, she's though actually the one who presented to me down on one knee as if she was proposing to me.

It was awarded to me, but it lives in her room because I told her it's as much of metal of as hers as it is mine. So you wanna show it Delfina? Come. Show them. Hold it for a moment. Thank you. Just wanted to show our pride on that.

Peter: Do you wanna tell Candice what you wanna be when you get older?

Delfina: I wanna be a Sick Kids Liver Transplant Doctor.

Mm-hmm.

Peter: That's her goal. Maybe two years ago during remote learning. We, she had to do a presentation on a community helper. Mm-hmm. And she picked Dr. [00:59:00] Ng. And Dr. Ng was amazing and, she interviewed Dr. Ing for her presentation, she actually pretended to be Dr. Ng and she spoke about it. It's actually have it on video. It's a, she did a really, really good job. One of the main things I guess we wanted, for her, we wanted to make sure that, that, this didn't define her life, right?

That she defined, her life. Right. And this was just, another aspect of who she is, right? And, you know, I think she's, I think she's done that. She's awesome.

Candice: So someone who supported you along your family journey has joined us today. Dr. Ng, thank you so much for joining us. I'm wondering if you two could please introduce her.

Betsy: Sure. Dr. Vicky Ng who was for us synonymous with Sick Kids, the care that we received and basically Delfina's Guardian Angel at Sick Kids, to be quite honest.

Candice: I'm wondering if you can tell us a little bit about yourself.

Dr. Vicky Ng: All right. Well my name is Vicky Ng and as you've heard from Betsy and Peter, I'm [01:00:00] Delfina's Pediatric Liver Transplant Physician at the Hospital for Sick children.

But maybe in terms of background, I can just share with our viewers that I'm actually a Toronto native. I was born and raised in Toronto. I went to high school in the North Toronto area. I went to the University of Toronto where I did two years of undergrad. And then I got into med school at the University of Toronto.

And then I did actually my pediatric residency. And then I actually went to the United States for a few years to kinda get my training in pediatric liver and pediatric liver in Cincinnati, Ohio. And then I came back to Toronto to be an attending position at Sick Kids, and I think there's no looking back.

Betsy: Dr. Ng, why did you specialize in pediatrics and specifically in liver transplantation?

Dr. Vicky Ng: Well, as you heard I did my residency at St. Kids and I'll say that actually being born in Toronto, I had always wanted to be a doctor that took care of babies and children. I think there's just something very unique about patients who are pediatric aged [01:01:00] and I think I really, really enjoyed the fact that there was a family behind every child.

And we know that wellness is so much involving the Moms and Dads right? And the siblings and the whole family unit and the extended family. And also when you're born in Toronto it was very clear to me that to be a pediatric doctor I would be trained at Sick Kids think it my into school that could actually the for sick children and get my pediatric, that's a pediatrician part.

And I think after I finished training in pediatrics, which is like four years of training, I had the option of actually being a pediatrician so I could be, you know, have an office or maybe work at the Hospital for sick Children in the general Pediatric. But I kind was that type of person that to know a lot about a specialized area.

So the idea being a specialist, I actually kind got born when I was doing my general training and I'd always thought the liver was a fascinating organ, not even for the peds standpoint, but when I was a med school and learning about the different systems. And I think one thing that I will say, which I think you guys can appreciate is I was always really struck at how [01:02:00] complicated or complex the liver was that, you know, you could have something wrong, but something else would be so right. And then how do you just sort of do that sort of balance to know when it's time for an organ to be so unwell? And then I thought was really cool that liver transplantation was becoming such standard of care.

I mean, predated obviously me becoming a hepatologist. But the idea that you could have a liver disease so severe and you know, for a lot of conditions where you can't replace the organ, to me it was pretty amazing that you could actually replace an organ and actually help that patient and you know, a child have the life that they deserve to have.

So that kinda all culminated together into sort of combining my love for children and pediatrics and why I didn't just sort of stop at the general pediatric care. Because I just felt like I wanted to know a lot more about an organ and liver and liver disease in, as a child. And, you know, replacing the liver of liver transplant and watching these kids grow up and realize their dreams. It was just like the perfect career choice for me.

And actually, working with patients like Delfina is a perfect testimony of why I do what I do.

Candice: [01:03:00] Mm-hmm. That's incredible. Mm-hmm. . This may be a very difficult question I'm wondering if there is an average day at Sick Kids, what your work is like for you.

Dr. Vicky Ng: Wow, that's actually is a bit of a challenging question. I think that one of the best things actually would say about my job is there's, you never quite know what your day's gonna be like.

And I probably say that there's not ever like a day that's like any other, because how can it be you encounter different patients who need you? And I think one of the things I'll say is that our days are kind of like a mishmash.

Some days more of one than the other. But it's kind like lots of things that include taking care of patients, which is the best part.

And you can take care of patients or help patients in the clinic. As an outpatient and patients go back home, you could be seeing and helping patients while they're admitted as an inpatient, which Delfina and Delfina's parents will definitely know, that we don't like to have our patients be inpatients all the time or as short as possible.

And then also a typical day for me could include something called endoscopy. Cause as [01:04:00] gastroenterologists are hepatologists, which is my training. Some kids actually need to have further investigations done in the form of a scope, so I could be scoping. And so that's sort of the patient taking care of the clinical care part.

But I think what's also really cool about my job is that there are what we call the "nonclinical parts", but help enhance care. And that's education. So teaching, teaching all the future generations of doctors who hopefully be able to be specialists in another province in Canada, in another country in North America are more cool.

Sometimes people that wanna be pediatric liver doctors come from Europe or Asia, Australia through Sick Kids. Delfina's family have certainly met a lot of what we call "fellows" who are people that have already trained to be pediatricians but now want to come to a big liver transplant Centre so that they can take some of that training back and basically proliferate expertise and outcomes, right? In other parts of the world.

And then there's other things called research and sort of what we call "quality improvement" or "patient safety", which is kind of like taking questions that we encounter. [01:05:00] And I always say one of the best parts about being at Sick Kids is a lot of things that we don't know are told to us by our parents and our kids.

We encounter things that is a puzzle or a question that's not really, the answer's not really there. We know a lot of answers to questions, but there are a lot of things that we don't know and that's sort of what I call the, the scholarly part or the research part, and we'll talk about that hopefully a little bit later.

But some of the questions that we still don't have answers to, and that's where we at Sick Kids are really proud and desiring to try to answer questions. But I think at the end of the day for my life, the typical day is I'm always sort of on the receiving end of parents or teenagers who telling or asking me something and I don't, I know that the answer isn't immediately there from the, the literature or from current clinical study.

And that could be like the major study and that's how really help generations of kids. We know that being at Sick Kids is so much more than the patient part and so every day is a little different balance.

And some days I don't have clinic or I'm not on call. Other days I'm on call and that's all I do. [01:06:00] So, you know, on the weekends if I'm on call, that's pretty well all I do because there's less people around to kind of do the care that you see Monday to Friday.

Betsy: Dr. Ng can you speak about the culture at Sick Kids and what's so special and unique about a child's transplant journey at Sick Kids?

Dr. Vicky Ng: I think number one, what I'll say about the culture, but Sick Kids is that we are so much more than a hospital. And I think that's one of the things why I actually really wanted to be a pediatrician, because I think, and at Sick Kids particularly, we recognize that the child is at the centre, but when we say we deliver family centered care, this is so unique to pediatrics, right?

The child's at the core, the child has the issue, but we know it's so much about making sure from an age appropriate standpoint that the child knows what's going on, and that the child actually knows that we're trying to help and we have to go and use all our different expertise and my amazingly smart colleagues and team members that together as a team, we make sure that that's known. They feel safe [01:07:00] and they know that we're here to help.

Then as you know, its families under care. At the crux of it is a Mom and a Dad who are everything, right? No matter what, health are not health. We need Mom and Dad to be healthy and educated and really part of a team to have the best outcomes. And so when we say a healthier child, a better world, which is the mission of the mission of Sick Kids, I think that's so true.

And why do transplant? Because a healthier child after transplant, after we've actually replaced the disease organ with a healthy organ, the world's a better. And I will say this, as I say, I want every one of my children had a transplant to shoot for the stars, go for their dream. And I'll know that wasn't possible without transplant.

And to do it at Sick Kids, where you know, you've met so many amazing of my smart colleagues, there isn't an angle that I wouldn't have someone to call. In my immediate team, in my extended team, and I think you guys would know this if there was ever a problem, there is my team outside of Sick Kids. I can pick up the phone and call somebody the hospital, say, "Have you seen this?"

Because [01:08:00] really at the end of the day Delfina's the core of why we do what we do.

Candice: And I'm wondering if you can even talk about what it looks like walking down the halls of Sick Kids for a patient too. How that is different than, let's say, what they would generally see in a different place?

Dr. Vicky Ng: Oh my gosh. Okay. I'm gonna tell you a funny story to make Betsy laugh. So absolutely.

I think the laws of Sick Kids and actually, you know, as we know, we're rebuilding the hospital so that it will only be, I'm sure, incrementally better and refreshed. But my children have always loved coming to Sick Kids and they will say, "Mom, why is it that there's a flying pig in the atrium?"

They're looking at the colored footprints on the floor and I just love it. My kids always use it, and they will laugh now as older kids saying, all kids see these

colored footprints and they're putting their feet on the footprints, right? To follow down the hallway on the main atrium hallway. I think that's super cool. You're not gonna get that in an adult hospital.

I think all the walls, you know, is just bright. And I think that you see, if you go to the elevator, how many times have I [01:09:00] seen our clown, our therapeutic clown in the elevators? And I think that is just so much of a very family centric, child friendly. It's not just the atrium parking lot.

There's a playroom for the siblings. It's not just that on every ward that there's actually a corner room that's dedicated with developmentally appropriate toys. It's not that, when you're admitted, no matter what age you are, we will have a Child Life Worker or some, a volunteer coming that will bring age appropriate stuff for the kids to do.

It's like if you come to the operating room and you need a procedure done, there's always people there to try to help the child feel more comfortable. And I think you don't get that in an adult hospital. Cause I mean, sure enough, when you're adult you're supposed to kind of suck it up and the kids are so resilient.

I think they deserve to kind of have, something that really is age appropriate to them. And we know that from the time you're a baby to age 18, there's a lot of different buckets of age. And I think that the amazingly talented and passionate and excited and devoted Child Life Workers and everyone else about, emotional support, [01:10:00] physical support, mental health, social, emotional. It's all there.

And actually, I just keep thinking of Delfina when I'm saying this, because I have to go back to the Family Centred Care Model. And this one thing that's so unique about the family is the fact that they had the extended family ever present in Delfina's room. And I would know if I came in that there would be an Aunt Lucy and they would all have a smile and just be really kind of up to date.

And I think this is what really makes me feel so, gratitude is that, they have family members we're gonna be there and try to help support them along the way knowing that they're gonna support the parents, right?

I think, you know, Betsy always just said that your sister and I always admired that so much because I didn't have a sister.

Wow. It was just like literally like her little mama. So that was really cool.

Peter: Just to jump on what Dr. Ng said there, we had a conga line of family members, the hallway visiting hours, I think it said two family members to a room or some, it that was a suggestion.

But I [01:11:00] mean, what Sick Kids does is it creates an environment where you're not focusing on the sick kid or "what's wrong with that child?" They create this environment where for long times after the transplant and we were released, Matthew still wanted to go to Sick Kids.

Betsy: He still does.

Peter: Yeah. He still like, there's so much to do.

Dr. Vicky Ng: Does he walk on those colored footsteps?

Peter: Delfina does that, but the facility is, world class and the way everything is set up with there being so many things to do is phenomenal.

What really sets Sick Kids apart from other hospitals is the staff there and obviously Dr. Ng, but the frontline, the nurses. The staff is just phenomenal. There would be many times where I saw not just Matthew, but other families that we met, the siblings of their sick kids.

They would be hanging out with the nurses in the nurse area, helping the nurses or [01:12:00] playing games with the nurses. You can't really put into words how important that is. And, just being treated like human beings and not the parents of a sick child.

Even just talking to us about something that has nothing to do, with liver disease or a liver transplant and just getting to know us and having a normal conversation. That stuff goes such a long way and it breaks up the monotony.

Dr. Vicky Ng: And I really wanna echo the fact that, you know, the Multidisciplinary Team and the extended medical staff is everything. I have the pleasure of being interviewed, but, behind the scenes. It takes a village to raise a child, a healthy to raise a child, but the village. So just really can't underscore that enough.

Peter: When we were discharged and from the hospital, we hoped we would never be back, obviously. But we wrote a very, long letter to the nurses and the staff on our floor there and just, thanking them for everything that they did for us [01:13:00] while we were there over the nine months or so. And I can't begin

to tell you how amazing the staff is at that hospital. That's, to me, that's what makes that hospital world class.

Betsy: Dr. Ng, can you describe what biliary atresia is and its treatments?

Dr. Vicky Ng: Okay, so biliary atresia is a disease that affects only babies. And it affects the bile ducts of the liver of these babies. If you think bile ducts like the plumbing of the liver, the normal role of normal bile ducts of the liver is to drain bile that's made in the liver into the intestines.

So biliary atresia means atresia or blockage, or obstruction of the ducts. That is typically first notice when the babies are sort of like one to two months of age. And by not being able to drain the bile of the liver, the bile gets retained in the liver and causes what we call [01:14:00] scarring and potentially cirrhosis.

The treatment is earliest detection. And the first clues of something happening most commonly is yellowing of the whites of the baby's eyes, or the yellowing of the skin, which is called jaundice. And unfortunately, jaundice sometimes can be viewed as, "Oh, it's just something that every baby has," because there's certainly a lot of well babies without biliary atresia that we have jaundice in the first one to two months of age.

Unfortunately, biliary atresia being a disease that you're born with, that one to two months can cause significant scarring. The treatment is to try to do a surgery, a corrective surgery that tries to reopen up drainage. So that bowel can not continue to be blocked up in the liver and drained into the intestine. And this surgery is called a Kasai procedure. [01:15:00] And its chances of success are highest the younger the babies are.

And as I mentioned, it can be picked up or diagnosed by yellowing of the eyes or by pale white stools or stool that are really light as early as even two weeks of age. And clearly the you can do the surgery, the better.

Biliary atresia is rare. It only happens perhaps one in every 15,000 to 18,000 babies. But in a place like Sick Kids, biliary atresia is unfortunately seen enough, that it is the most common reason why liver transplant is needed.

So when we talk about treatment, liver transplant is sort of like the mixed surgical procedure, if the Kasai surgery does not drain or does not create drainage.

Peter: If Delfina's Kasai had actually been successful and worked, what kind of life would she have been looking at, compared to kind of what [01:16:00] she's living now?

Dr. Vicky Ng: Yeah, so when we talk a Kasai working, we kind of break it up into buckets. So what happens is the first of the Kasai working is that there's clearance of jaundice. Yellowing of the eyes becomes white. The skin becomes pink again. And blood tests will show that the very high bilirubin that kind of led to us meeting, being the hepatologist meeting the patient will resolve and we normally want that to happen within three to six months after the Kasai. So that's sort of like the first bucket of get past that phase. You don't need to meet the transplant program in the first year of your life.

If that is the case, which is about maybe half our kids will actually be able to drain, then we actually really are very hopeful. These kids generally will do well.

But remember I was saying to you that because of that first two to three months, when the bile isn't draining of the liver, it's already caused cirrhosis or scarring of the liver.

So what we're hoping for if the [01:17:00] Kasai is working is that the baby's growing becomes a toddler and a child. So new liver is growing as well. So the hope is that as the liver gets bigger, that's actually more healthy liver than the small part of the liver. And I mean the small whole liver that was actually scarred.

And we have, kids who graduate from Sick Kids at age 18 still with their own liver and go to an adult program. And they're not followed by the liver transplant team, but they're followed by the adult non-transplant liver doctor. Okay? And some of those kids, will do very well. And some of them will start having problems, even after that first bucket can happen, what I call the "middle age biliary atresia".

So between age two to age 16, you can have different kids that may need transplant, the transplant team at age four or age eight or age 12, but you have kids actually connect, be doing okay.

So pleased that we're talking about Delfina had very little of a complications that we may have counseled you about, which we're gonna talk about. "What are the risks of having a liver transplant as a child?" So in every sort of

[01:18:00] outcome, Kasai, no transplant or Kasai, and then transplant, you can have great outcomes. You can have, very complicated outcomes.

Peter: So living with a Kasai is the preferable?

Dr. Vicky Ng: It's preferred in the standpoint that, "If you had a Kasai that drained and you don't need transplant until you're 12 or you're 18 or or never, is, you don't need the immune suppression." That all our post transplant kids' need, right? And so that itself, with all the, all the counseling we do would be a win.

But ultimately we'll say we, we have transplant as something that if you need it, you're gonna get it. And we'll help the families understand because we'll take the risk of a immunosuppression, because that's what's the right thing for her, right?

And so we can talk about risks when, when you have a choice, but when you know it, it's what you need, then we're gonna make it the best. I think the stars were meant for her to transplant and have this outcome, right?

Peter: That's no, that's, that's great. I mean, we've always kind of wondered that because we are like, you know, "She's the liver transplant was successful. She's leading, she's thriving."

Dr. Vicky Ng: She really is.

Peter: "Why, why would we even [01:19:00] hope to live with a Kasai? We shouldn't have just got her liver transplant right away, right?"

Betsy: That's what I said it was.

I actually was saying exactly to Candice that this is a timely interview because Delfina's very first admission to Sick Kids was November 24th. And within two days she was confirmed with the diagnosis of biliary atresia. It's so weird how it feels like forever ago, but also just yesterday where I was sitting in, in her room where Dr. Fatto had come in and explained and the Y diagram and et cetera. So just, it was very timely.

Peter: Wow. Crazy, crazy.

Dr. Vicky Ng: I think one of the other amazing things about Sick Kids is that, I mean, I don't mean this in a trite way, but we are kind of like a one place we

can, we can basically, I met you and if she needs a transplant, you're staying right here at Sick Kids and we're just gonna involve more people.

And I think that's one of the best parts of it from a family standpoint. Cause I think that there are other parts of Canada where while they can do the Kasai [01:20:00] surgery, but if the Kasai surgery doesn't work, then and refer referral out province sometimes needed. And you can imagine how up that is, right? To have to travel from Atlanta, Canada, for instance, where we do a lot of liver transplants for kids with whose Kasai don't work. It's a bit uproot, right?

And in this case, it's kind of like, "Okay, I'm at Sick Kids," but now actually you're still getting admitted to the 6th floor and you know what I mean? You're still seeing some of the people that you meet additional people. And we really I think that's one of the things I'm most proud of because we really build expertise, right?

All step to the way, whether it's Kasai and no transplant or Kasai followed by transplant. I think have that comfort of knowing if that's the case, we're ready for you. And if we sometimes say it's a bit earlier than you thought you might have wanted to, we're gonna get there. Really, you know?

Have you understand, and, you know, eventually look back and say, "That was the right thing to do, right?" We don't wanna do things too late.

Candice: Right. So thinking about the timelines and you spoke a little bit about risk, I'm wondering if you could talk about what are some of the difficulties or the risks with pediatric liver transplants and if there's [01:21:00] any differences between that and adult liver transplants?

Dr. Vicky Ng: Yeah, thanks for that question. I would say big time there are differences because if it was all exactly the same then you wouldn't need to have a pediatric liver transplant program and adult liver transplant programs. And I think the obvious thing is, first thing I'll point out is size.

We're talking about biliary atresia. I just finished talking about how it's a diagnosis that's made when you're a baby and it's the most common reason why pediatric liver transplant programs exist. And the average age, these kids are between one and two the majority of the time. So these kids are like five or six or seven kilos.

And if you think about that, then everything smaller when it comes to reconnecting plumbing, reconnecting arteries, reconnecting vessels, vein. We

have amazingly skilled liver transplant. Surgeons are great with that. And so I think that's first and foremost. I think the surgeries technically has differences and challenges that come with smaller size.

Thanks again Mom. We touched about this already and you know why we don't just go ahead and do liver transplant when we first meet [01:22:00] these kids, when they're one month, two, month, three months of age, is that they're obviously, the bigger they are, the better they are. And even an extra kilo, like instead of being 3.5 kilos when you're born and being 5.5 kilos, when you are transplanted. That actually would help as well.

But I think the other thing is that it's the immune suppression medications, right? If you're, 35 and you, graduated from college and you start lifelong immune suppression, which is the current standard of care still, that's very different from when you're six months, nine months of age. In your brain and your body is still needing to grow and go through all the phases of development that immune suppression can, sometimes without the meticulous expert care of our team can sometimes really wreak havoc and all the complications we've talked about on the kidneys. On getting unique post transplant cancers.

It's a lot different when your kidneys are still growing or when your brain's still developing. Or if you get cancer and you need additional medications, like chemotherapy on a little body is much tougher than when you're an adult. [01:23:00] And so that really speaks to why.

And also the other thing, cause we do transplants any age from the fact, from literally days old to 18, they're different patients, right?

If you're 18, you're different from 16, you're different when you're three months, nine months. And so I think that those things make for difficulties and challenges. Whereas if you're 35 or you're 55 or you're 65, you're kind of an adult patient. And I think some of those things are a little bit easier and to explain.

So I think those are some of the challenges that I think I would probably bring up. And it's not inconsequential, a lifelong immune suppression in a developing child who still has lots of growing and development to do. And as I said, our goal is for them to graduate from us and go to college and shoot for the stars or do whatever their dreams are.

And so we have to really bear that in mind. So that developmental post care is also really, really important.

Candice: Since we're talking about immunosuppressants, I'm wondering if you can talk a little bit about your research in efficacy, safety, and the potential benefits of immunosuppression minimization in pediatric liver transplant [01:24:00] patients?

Dr. Vicky Ng: I'll bring up two studies. There's actually a lot of work going on, but I think these two are the most relevant to our patients.

So we know that lifelong immune suppression is the current recommendation and all programs across the world in 2022 as it was in 2015. Our hope one day though, is something called tolerance, which is the ability for a transplant patient to no longer need immune suppression that you can withdraw will happen during Delfina's lifetime.

There was a big study called iWith. I stands for immune suppression. With stands for withdrawal, which was a MultiCentre North American study funded by the National Institutes of Health. And Sick Kids was the only non-US hospital that was allowed to enroll patients. And essentially what the study wanted to do was try to study the ability to safely withdraw kids off immune suppression, very gradually with very [01:25:00] meticulous monitoring and monitoring through the graft.

I think the long story short is that we know that if there is going to be an organ for which immune suppression can be withdrawn, it will be the liver first because the liver is known to be a very immunotolerant organ. What we learn from iWITH though. We're not ready for primetime. We are not ready to say that if somebody has done really well for four years or eight years from the transplant surgery with no rejection and perfect liver numbers, we've learned that normal liver numbers cannot tell the whole story. And that we cannot with our current knowledge predict which excellent outcome child can safely withdraw without developing rejection.

However, the study was instrumental because we were able to study many, many kids and obtain lots and lots of blood samples during our monitoring, with the goal that we might be able to look for a biomarkers in the blood and have two very cleanly defined groups. Those who withdraw and did not rejection, [01:26:00] and those who withdrew and did develop rejection while off immune suppression. So that we fast forward one day, we might be able to say, "Oh, but you're doing really well. Let me take a sample of your blood and let me see if I can look at the bio marker panel in your blood to see whether or not you look like you have clues that you'll be able to safely withdraw."

So that will be huge for the community to know that this current teaching, which lifelong immune suppression isn't lifelong. That would be tolerance, is actually the Holy Grail. This is what we all are in transplant hoping to accomplish one day. Ok? So that speaks to the safety and our desire and our commitment to our kids, particularly. Obviously it'd be great for adults too, but for our kids because of all the potential risk factors.

The second study I was gonna talk about is another, it's called iMALT. I stands for immunosuppression and M A L T stands for medication adherence after having a liver transplant. So the background for this, and this was actually a study that we did here at Sick Kids in collaboration with them [01:27:00] people at McGill, Montreal, is that we know that kids who've had a liver transplant, if they do really, really well and they become their typical teenager, typical teenagers typically don't listen to their parents. And the parents who actually were able to make sure that they were very adherent to their medications in the first 10 and 12 years of life may actually start being nonadherent, skipping medication doses. And the thing about liver transplants in particular is you can miss a couple doses or even several doses, and if you don't tell anyone, it may not be inherently obvious.

You're not getting a little red sign from your ears saying, "I skipped my dose of medication." And so what we're noticing is that there's, there's a high risk period where we call when you're an emerging young adult and then liver kids, it seems to be somewhere between age 21 and 29, which is the highest risk period that the age group where most young people or kids who had a transplant are having graft failure or dysfunction and need another transplant because of rejection.

And [01:28:00] so the iMALT study in recognition of the fact that in the pediatric arm when they leave as at age 18, are heading into a high risk period, is actually working on coming up with this intervention through interventionists who are texting and calling and emailing teens who have been identified to be erratic with their medication taking the immune suppression. And trying to see whether those who receive the intervention regularly will actually have less rejection.

Than a control arm. Seeing kids non-erratic, who being randomized to be in the control arm so they're not getting all these texts and messages and see whether their injection rates are different. So the long and the short iMALT suggest and is exploring that maybe we could be offering more during the teenage years to try to help these kids develop those life skills and efficacy to understand how important immune suppression is. Because it's normal for a teenager to kinda

think “I’m taking [01:29:00] medication, I feel fine.” My Mom is really nagging me.

So this is one thing about pediatrics uniquely is that, you know, you’re different in your first five years of life, 10 years of life, 15 years, 20. You’re a 45 year old adult liberal transplant recipient, you’re probably, you know, more or less the same if you’re, you know, cognizant and you know, they’re mindful when you’re 55 and 65. You’re still doing that, not with kids.

So this is why the iMALT study is quite revolutionary. So lots more to talk about research, but those two, iMALT and iWITH have been recent studies that Sick Kids that’s been heavily involved with towards our goal of having our kids have a graft that will live forever and ever until the time of a natural life span.

And that’s particularly important with Delfina because her liver came from her Mom, and we want that liver to not to last a very long time.

Betsy: But even the immunosuppressants, it just speaks to how personal Dr. Ng is in tune with us and with Delfina where before I could bring it up, Dr. Ng at one of the last clinics was, [01:30:00] like, “How’s Delfina for her immunosuppressants? Do you think she can handle switching from the liquid dose that she loves and was yummy. To the actual pill form?”

I was like, “No, she still wants the liquid.” And sure enough she immediately, now she, she’s a pro. She loves showing off that she can do it without water. She just pops it in.

Dr. Vicky Ng: Isn’t it amazing? Oh, I’m so glad. She’s a trooper. That’s amazing.

Peter: Oh my God, it’s so much easier.

Dr. Vicky Ng: It’s easier, right? Oh my gosh. So much easier.

You know what, you just always boggle at how resilient and how smart our kids are. Like they’ll come up with ways to help and you just have to listen to them, right so that’s amazing.

Betsy: So if a child has a living donor, how does it work in terms of the collaboration between Sick Kids and UHN with respect to that living donor program?

Dr. Vicky Ng: Yeah, thanks. Thanks very much. Because you know, you really can't talk about how great Sick Kids outcomes are with liver transplant without bringing up the Toronto General Hospital. And this amazing, unique partnership that Sick Kids has with UHN, which is called [01:31:00] University Health Network. Formerly known as Toronto General Hospital. We're part of the University of Toronto Transplant Institute.

And so every child who we first meet to talk about liver transplant and when these pediatric patients undergo the liver transplant assessment process, so they're coming from Winnipeg or they're coming from IWT. They're coming here with a question is, "What's the role of transplant in the treatment plan for this child? With biliary atresia or whatever diagnosis it is."

It's usually a two to three day full of consultations, blood works, investigations, imaging and all that. Their visit with me at the hepatologist or one of my hepatology partners and their visit with the liver transplant surgeon, one of the three Sick Kids liver transplant surgeons who do the surgeries, will always at that early juncture bring up that, "We need an organ to do liver transplant."

Deceased donor organs is the current standard of care. However, in our [01:32:00] jurisdiction, in the Greater Toronto Area, in Ontario and in Canada, we know there's many more patients who are waiting for an organ than there are organs available. And we also know that particularly for our pediatric patients who are small, getting a healthy organ from an adult deceased donor is very challenging. We know that from stats. And so probably about 20 years ago, we did our first live donor liver transplant. More than that, actually we did our first pediatric live donor liver transplant in 1996.

Probably in the past 15 years we have done more and more such that now we do so many because we just know it's a faster way for our pediatric patients to get a quality organ and all the benefits that can come from identifying an organ and being able to control and plan for liver transplant surgery rather than waiting. And we know that deceased patients who don't have a live donor option wait longer, [01:33:00] than patients have a live donor transplant.

So we talk about it right from the get go. The parents, I'll tell you that the most common live donors are Moms. The next are Dads. It's probably a little bit of the size too because Moms generally are smaller than our Dads and we have the majority, our patients are babies.

So I hope I can answer the question is that we are our partnership, so we bring it up right from the get go. If there's any interest, we have very clear instructions

on how any interested adult, and live donors have to be age 18. We tell them to be fairly healthy. Because if, you know you just had a heart attack in the past year, probably you're not gonna have the best outcome.

And the Toronto General is very, very obsessed. And we've had excellent, excellent donor outcomes is by choosing good outcomes. But what we'd rather have anyone who wants to go and put in their health history and have the live donor program who are adult experts work of the, the donors.

What I'm trying to say is that live donors brought up right when we meet the pediatric recipient [01:34:00] and the live donor program has been a tremendous asset. And thirdly, you know, our outcomes are excellent because we try to get as many of our kids transplanted as soon as possible.

And number four is, we know that in the western world, the Toronto Transplant Program, the city of Toronto does the most live donor transplants for adults and kids anywhere in the western world. And that's because of this partnership. So peds patients will benefit, an adult patients obviously benefit. And we need, we couldn't exist without UHN live donor program. So I really wanna do a big shout up to them.

Betsy: Obviously the collaboration is why we are here today. It is why my daughter is healthy and thriving. Why we are obviously so happy. Fast forward eight years later from the fear the unknown to absolute delight.

Peter: Believe me, eight years ago tomorrow, we did not think we would be living a normal life and , all the work that you guys did and like as [01:35:00] much pushing as, as we did to, to get a donor and, and that sort of stuff. It was with the goal of just coming home and just having a normal life, which seemed completely out of the realm of possibility at that point.

Dr. Vicky Ng: From the day that we looked up you and said she needs it and we invested her, we were ready to go that next minute. And everything that happened till the date of the transplant surgery was waiting for that organ. And as you know, she was always listed for deceased donor organ.

And we told you that the wait long is long, but if there'd be a live donor, that came sooner we were going. And it was just a matter of working in a collaboration partnership. Its like, "Let us know when a live donor is cleared cause we're gonna move, right?"

Peter: Your answer there about the longer we wait, the more her health deteriorates was the driving factor in us pushing for a live donor.

She was fairly stable, especially for her condition at the time. But we didn't want to watch her deteriorate into a point where, she rose so high on that deceased list. [01:36:00] Right? We wanted to make sure that she could recover quickly, and get home quickly and we could become this normal family and do these normal things, and it's a fantastic program. Obviously the partnership between UHN and, and Sick Kids because of it, it allows for families like us to come home early and live these normal lives that, when Betsy was pregnant with Delfina, we had this image of the two and a half kids and white picket fence and Christmas mornings and all that stuff.

And then obviously you get thrown for this massive loop, and all those thoughts go out the window. But you guys obviously were able to provide us with that, the realization it was a little bit longer than we had initially thought when she was pregnant, but meant we got there. So that's, that's the, that's the most important thing.

Dr. Vicky Ng: Well, it's my hope that your story will give other families with perhaps a child who waiting for transplant or biliary atresia hope, because we certainly know that outcomes are very varied. And we certainly, my heart breaks when there are some [01:37:00] families that don't have a live donor identifiable, not because they didn't want to try, but, as we all know, health is not something we ever take for granted.

And there are many families who, both parents and anyone that they could think to have set forward get ruled out because why we keep on doing this, it's because the live donor program is so skilled and expert at ensuring that the right donor at the right time is utilized isn't. And that's when it's really hurt. And there is a percentage of kids that have to wait for deceased donor because that is a standard of care and there isn't a live donor to go sooner. Right? So, but I think it's really important for people to hear that a live donor can really, really help. And outcomes can be really good because of exactly what you said, Peter. But also be mindful that if anyone's listened to this podcast, what you can do is make sure that you go on BeADonor.ca website and register your intent to donate, because research will show that if you register your intent to donate and something unfortunate happens and you didn't have a chance to share with your loved ones, the fact that you [01:38:00] personally said on this website you wanted can really help change lives. And we know that one donor can save so many lives.

I'm sure Delfina's story will, will resonate and as she becomes a young lady, we'll see what she does to change the world. So thank you for that opportunity to kinda have you be an ambassador for us.

Candice: Sick Kids is a pioneer in research, in innovation. In 2009, the world's first cardiac surgery in utero, helping to save children who hadn't even been born. 2014 North America's first incisionless bone tumor surgery using MRI and focused ultrasound.

These are remarkable things that are happening here in Toronto and I'm wondering if you could speak a little bit about some of that innovation at Sick Kids and what's to come?

Dr. Vicky Ng: Wow, how much time do you have? Yeah, so I think, I'll just, maybe I'll highlight to you new knowledge. Using science to answer questions is a lot of what Sick Kids is about. And that can come in the form of bench research, like in the lab doing something that you know, may not be realized by a [01:39:00] parent for another decade.

Or it can be clinical research, which we already talked about, but can certainly be also translational research by a question of the bedside. I'm gonna bring up two things. One of them is actually really relevant. We've heard a lot from families whose kids are like, you know, 10 years out from transplant and they're doing really well and they almost feel like, oh, it's almost like a shift.

So much attention early on in the first, before transplant we're seeing like every week, post transplant we're seeing a few times a week, and it kind of gets spread out by the time you get up to five or 10 years that we see you once per year. It almost feels as if like, "Whoa, are we like not? Is everything okay?"

You know what I mean? And Delfina's amazing, which is why we know it's okay to see you once per year. We've heard some parents tell us, and I think you guys have heard of the star zone network, which is basically parents telling us that, "Are you really hearing what we're saying when you kind of see us once per year?"

So something called PROM, patient reported outcome measures is now very important in optimizing best outcomes for our kids. Hearing what our patients say, [01:40:00] patient reported outcomes, that doesn't involve a doctor. So the Hospital for Sick Children is the hospital to first develop a PROM, or a quality of life tool, specifically for pediatric liver transplant recipients.

This is called the PELT QL. Pelt is pediatric liver transplant. QL is quality of life. Before the PELT QL was developed, we only used tools for research that was for all chronic diseases. So if you could have had renal failure, you could have had asthma, you could have had lupus. We all use the same tool.

You can imagine if you're a pediatric liver transplant recipient, you have questions and thoughts that are unique. So the PELT QL is one innovation that's now being rolled it across the, the many, many sites, and we think that this is actually keeping up with all the chronic diseases that do have disease specific problems.

So that's translational research. It's actually because a patient, actually a bunch of parents and patients said, "Hey, how are you doing this?" And we're actually now coining it, "making the invisible visible." Because actually, until our kids [01:41:00] articulate some of these concerns, we don't know they're, and we think it's like a vital sign.

It's like, you know, "You measure your blood pressure before there's a problem. Why aren't you measuring sort of what we're seeing about our quality life?"

The second thing I think is now, so something very, very on the opposite end is in the bench. And the lab right now, there's a lot of work with something called IPS cells, which are sort of in is what we call induce prepotent stem cells, which you can actually grow what we think organoids from blood or from skin

Sick Kids Episode: cells.

Dr. Vicky Ng: A lot of scientists at Sick Kids and across the world are actually now looking at ways of actually maybe trying to grow a liver cell or growing a bile duct cell, which is very relevant, what we call cholangiocytes. And that's gonna be amazing for modeling disease in a dish, or actually testing out new drugs on these cells that you can actually create a disease in a dish.

And one day can we even create an organ. Can you imagine a day if you needed to have your biliary atresia, cirrhotic liver [01:42:00] replaced, we could actually grow a healthy organ. We didn't have to do surgery on the Mom and have Mom be a patient for several days and have you to recover. That would be huge.

So those are land breaking things. Organoid creation is actually really big. So I'm probably giving you two examples where I think Sick Kids have been really involved in hopefully leading the field and will change care.

Candice: Amazing. I'm gonna ask everybody a fun question. We'll ask Delfina and Matthew to answer first.

If you were a tree, what kind of tree would you be and why? I'll ask you first Delfina.

Delfina: I would be an apple tree because apples I eat.

Candice: And what about Matthew?

Matthew: I would be an oak tree because I like the word oak.

Candice: Amazing. I like that. And what about you Dr. Ng?

Dr. Vicky Ng: I think I would be a maple tree so that it would have maple leaves because we are a Canadian. And there are a lot of connotations and the beliefs of the Toronto Maple Leafs hopefully will do well this year. Right? Sports fan, loving team. Can we only hope?

Candice: Yes. [01:43:00] Our big hope. That's fantastic. And what about you Betsy?

Betsy: Well, Dr. Ng was gonna say, "she's stole my answer." I was gonna say the maple leaf too because for me, obviously it symbolizes Canada, and I've told Matthew and Delfina so many times that we're very lucky to have been born in Canada. That, you know, we were born in another country, that there wouldn't be a Sick Kids that we wouldn't have had the care that we had in Canada if we were another one. I live and breathe everything in, in so Canada, I think, I think that would be my answer as well as the, is the maple tree.

Peter: You guys are missing the most obvious tree. I mean, guys, seriously like palm tree. Like it's obvious. Come on, come on.

Dr. Vicky Ng: I'm actually surprised my second choice would've been a Christmas tree, cause then I'd always glittery and all love. Right? That be cool. But I thought, like as Betsy, I thought let's go Canada.

Candice: I just wanna say thank you so much Dr. Ng for joining us today. We're so grateful that you could [01:44:00] share all of this amazing information. And for the remarkable job that you and your team do at Sick Kids. You are unlike any other.

So thank you so much for your time. We're incredibly grateful for all you do and everything your team does.

Dr. Vicky Ng: Thank you for having me Candice. And you know what, Team Delfina, have a wonderful rest of your weekend. And so nice to see you guys online until I see you again in person at Sick Kids. Okay. Thank you so much.

Love your t-shirts by the way. Bye.

Peter: Bye Dr. Ng bye.

Betsy: Good job. Good job.

Candice: You guys are amazing. Thank you so much for sharing your family's journey and for supporting the community as a whole and for encouraging other parents and, and being that bright light.

And thank you so much, Delfina and Matthew for being part of it today. We really appreciate you letting us steal your parents for a little while to ask a bunch of questions. And thank you for being so brave and so courageous and sharing. Thank you.

Peter: You know that she had a transplant too.

Candice: My Mom's my donor too. [01:45:00] Mm-hmm. Yeah. So we got some pretty amazing Moms, don't we, Delfina?

Thank you so much. Thank you guys.

Betsy: We we're thrilled to do it.

Candice Coghlan: Don't forget to subscribe to Living Transplant Podcast, wherever you're accessing this today. Please share with your friends and if you have any ideas for future podcast episodes, you can reach out to us at livingorgandonation@uhn.ca.

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