

Season 4 Episode 3: The Rest of Your Sight Life

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

I was fascinated when I got to sit down with Amber Needham and her living donor, Kathy. We discussed Amber's book, *The Blind Girl Sees*, and how she lost her eyesight twice from unique situations. Amber, Kathy and I talk about their remarkable journey as Amber went from 20/20 vision to blindness and how she was given a second chance with sight when Kathy donated stem cells from her eye.

We're later joined by Amber's ophthalmologist, the amazing Dr. Clara Chen, who talks about fascinating innovation in science with stem cell transplants, the healing properties of amniotic membranes, and how her work is [00:01:00] a lesson in humanity and the strength of patients. Please enjoy. It is my absolute pleasure today to have Amber and Cathy with me here today.

Thank you so much for joining me. Thank you. Yes. Thank you for having us. Amber, I'm wondering if you can tell our listeners a little bit about yourself.

Amber Needham: Well, I can say that, um, uh, my name is Amber Needham and I live in Southwestern Ontario. Prior to my vision loss, I was just, I was living life large and I still do, but I was living life large.

I was traveling. I was teaching the two very, very things I love the most, which is again, fitness and art. Uh, I am also, um, an author, uh, just as of last year. And yeah, I, I, you know, a site or no site, um, I love life and, uh, I always look for opportunities and I believe that we're all here for a purpose. And so I go looking for another purpose.

Candice Coghlan: That's [00:02:00] beautiful. Thank you, Amber. And what about yourself, Kathy? Can you tell us a little bit about yourself?

Kathy O'Toole: Yes, I'm Kathy O'Toole. I'm also from southwestern Ontario. I'm a retired registered practical nurse. I am 70, but I still, I do teach PSWs in the clinical setting. It's a very part time contract job, which I thoroughly enjoy.

It keeps, keeps my mind going. Amber and I, we have always known each other, our paths. Constantly crossing throughout the years, we started out as acquaintances. She was actually my esthetician. Um, and then after that, she was actually my yoga instructor and then we ended up in the same MLS business together and that's when we really.

Connected yeah, and I knew she was. I knew she was site impaired, so we started getting together and we helped each other in the business. [00:03:00] And then we've just become very close

Amber Needham: friends.

Candice Coghlan: So, Amber, um, bringing us back, um, at 50 years of age, you suddenly went from having perfect vision to becoming visually impaired.

How did that all, all come to be and, and can you walk us through that journey of how this happened?

Amber Needham: Yes, I remember it like it was yesterday. Uh, again, like I said, I was living life large. I was, you know, teaching and traveling. And, um, I have a fantastic, uh, perfect vision in my left eye, right eye. Um, due to a previous condition, um, I could see out of it.

However, there, there was, the lid was like a lazy lid. It would come down over the eye. So I still had vision and, uh, but anyway, within, within 30 days, there was some [00:04:00] significant changes with my vision and it was rather alarming. Um, by 60 days, I couldn't count fingers in front of my face. Five inches away, and it was the most scariest time I've ever had.

ever had to experience. Um, because the ophthalmologist at the time couldn't tell me why. So she, um, decided to ask if Dr Chan would take me on as a patient. And luckily, by the grace of God, she did. My previous condition is S. J. S. Which stands for Stephen Johnson's Syndrome. And Dr Chan will tell you that it's it's a severe inflammatory disease.

And so getting back to my vision loss 60 days and I just couldn't see anything. [00:05:00] So then one day I got a phone call and it was my girlfriend and she asked me just a couple of questions. She said, What eye ointment do you put in

your eyes at night? Um, which I did every single night to, um, to combat dry eyes and, um, the, the friction when I'm in REM sleep.

So this. was a part of my life since I don't know, since I was 16, I think. And, um, I told her and she said, okay, she said, how many tubes do you have? Knowing that I used to buy this product by bulk. So she said, okay, uh, don't put them in your eyes. tonight at all. Um, I'll see you in the morning. She showed up the next morning to tell me that there was a government recall on the product.

I was blown away because I was not informed. And what had happened, the product was on recall. Because it, um, had [00:06:00] frozen in shipment from the manufacturer. So, I was putting this stuff in my eye and it has small traces of sodium in it. Which when frozen turned to crystals. And I was scratching my cornea during REM sleep and was not aware.

So that's why my vision went downhill so quickly. It was because I was looking through, I could see my retina. Um, my vision was fine but I was looking through a very shattered. Once we learned that, then Dr. Chan was able to, you know, get a plan of action going, but it was, yeah, it was the most scariest time of my life because everything I'm, I'm self employed.

I've, I've been an entrepreneur my, my whole life. And, um, yeah, it, it, you know, it changes. Um, you got to make some very quick decisions. Very, very quickly when you're taken out of commission.

Candice Coghlan: So your, your [00:07:00] vision went from being able to, to see perfectly to, to being close to blindness within

Amber Needham: days. I was, yeah, Dr.

Chan, I was. blind at that point. And if we weren't able to get the inflammation down and, and she had tried a couple of different procedures before we, um, went to the idea of the potential transplant, the stem cell transplant. So we tried these other procedures and it. Totally unsuccessful. So, um, I was almost a year and a half with absolutely no vision, none.

Candice Coghlan: And so how did you? Managed to change your lifestyle that quickly. I mean, having to pivot from what you were living and an entrepreneur and doing [00:08:00] everything on your own and running your business to now being thrown into a medical whirlwind of having to figure this out. How did how did that

Amber Needham: feel? Like I said, it was the scariest time of my life because I'm usually a Kathy will probably tell you my personality is one of, I'm very organized.

I'm very methodical, you know, um, I plan things out and that don't, that doesn't work now. So, you know, the best thing was, is that I, uh, I'm so blessed with having such great friends and they all jumped in. Uh, even though I had a very difficult time asking, very independent I am, and, um, especially at that time.

And they just, they just took over. Somebody said, okay, I'm taking care of your yard. Someone said, you know, I'll take care of your groceries, you know, another one. They just all jumped in and, [00:09:00] um, made sure that I was, I was fed my dishes, you know, like my dogs were looked after because I had two at the time.

Um, and the calmer. You remain and, you know, try to just keep your cool and, um, it all works out. It just works out.

Candice Coghlan: And at what point in this journey did Dr. Chan discuss a potential stem cell transplant for you?

Amber Needham: When we had tried the other procedures and they had failed, um, I just kept saying, what's next?

What's next? What are we going to do now? And Dr. Chan was so good with me because I just was not going to settle, you know, I wasn't going to stay blind. So, um, she spoke to me about stem cell transplants and, um, the, the procedure, and it meant that, uh, I had to find my own donor, which was again, like very, very scary because not only can I not [00:10:00] see, now I'm going out there and asking people, um, would you help me in a very, very intimate, personal way?

And, um, yeah, that was a real growth for me because. I was not the type of person to ask for help for much of anything.

Candice Coghlan: We talk about this a lot, that it's one of the only medical situations in the world where they say to you, your best possible scenario is to have a living donor. But you have to go find that, and that's a huge barrier for a lot of people, and like you said, especially if you are a very independent person who likes to take care of yourself.

So how did you go about doing that?

Amber Needham: Uh, I was, I was being divinely guided through the whole thing because events and situations just fell into place. Like with Kathy, I was chatting with [00:11:00] a friend, a common friend of both of ours. And Kathy just came up and, and started to get involved in the conversation and, and I was explaining to both of them that other procedures had failed, but I was still optimistic that I could get my site back through this stem cell transplant.

And, um, Kathy being a nurse, she just said, what blood type are you just like off the cuff question. And I told her and she said, Oh, well, that's my blood type. And it just like, when I say things fell into place, Candace, they did like, it was unbelievable how things transpired in a perfect way. And so it just turned out that we both hopped in the car, went to one of my Dr.

Chan appointments and Dr. Chan was able to meet Kathy for the first time and answer Kathy's questions regarding this procedure. [00:12:00] Um, and

Candice Coghlan: Kathy to. What was your, what was your thought process when you heard Amber talking about what she was going

Amber Needham: through?

Kathy O'Toole: Well, I was so curious because I'd heard part of the conversation, so I just kind of butted in and said, you know, like, what's going on?

As Amber said, I knew, I knew the other person, so I felt comfortable enough doing that. It was exciting. It was scary. But at the same time, you know what, if I was in that situation, I would want somebody to step up to the plate. Sorry.

Amber Needham: Yeah, it gets, it gets very emotional for both of us. Um, because I was blown away how willing she was and, and how much compassion she had and, and care for somebody that she really only knew casually.

And not knowing a whole lot about it. So, oftentimes I'll come to tears too. [00:13:00] So yeah, so

Kathy O'Toole: for me it was just kind of a natural process. Like I'm a, I'm, I'm a giver, I'm a helper. So it was like if I could, if I can give somebody their sight back, or possibly their sight back, I mean to me that was just amazing.

But that could actually be done. So when I went to see, when we, when we went to see Dr. Chan, um, I had to have an eye examination there and then it was

discovered, um, that I had a little problem with my eye that I hadn't known and my optometrist had missed, but I had, um, I had pressure on my eye. So I had to have a procedure done to lower that pressure and then I was still able to go on from there.

And, and that was, Basically a nothing like there was no recovery time. No, nothing. Um, so after I was finally, well, I wouldn't say I was accepted because I was refused because of my age. [00:14:00] And I think at that time, I was about a year past the age, so, you know, I was denied, so I was very disappointed. I was inwardly angry.

I'm sitting there like, why? If we meet every other way, what does age have to do with it? So a few weeks, I forget exactly how long, but a few weeks had gone by, and they decided that because we were such a good match for each other, that we could proceed.

Amber Needham: Yeah, the, the transplant program, the stem cell transplant program for the ocular part was fairly new.

And I was one of the first ones to have a stem cell transplant. And that's what our, my, um, transplant coordinator had said. She said, you know, you guys, she says, I've never seen such a perfect match. But she said, you know, unfortunately, the criteria is is that they have to be a certain age. But yeah, they called back and she says, I've got some really [00:15:00] great news for you.

She said, we've decided to overlook Kathy's age because it's not likely you're going to have a donor with the match as perfect as this is. Yeah. So it was November the 6th, 2015 that we both went to surgery.

Candice Coghlan: What was that feeling like when they told you, Kathy, you know what? It's one year. If this is what you want to do, we're going to go ahead with it.

Yeah,

Kathy O'Toole: I was excited. I was very happy for Amber that she could possibly, I mean, we didn't know if the stem cells were going to be strong enough. We didn't know they were going to work, but it was such a positive match. It was almost like we were in the same family. So, um, yeah, it was very exciting. It was scary at the same time, even though Dr.

Chan had explained what was going to happen. And to me, there was really no risk. The risk was more. At Amber's end. [00:16:00] Um, so yeah, like for me, it was to show up. We'll do it. You go home. You're fine. You know, which is basically, which is basically what happened. Like, we both went back for checks the next day and so forth.

And then Amber continues those checks to this day. Whereas I don't like for me, it was eyedrops and for a few days and boom, bang, I'm done

Amber Needham: and she was fully healed in within a week. She was Back driving her, her cornea had completely, um, resurfaced itself.

Candice Coghlan: Whenever I talk to donors, as a recipient myself, our biggest fear when I chat with recipients as well is what's going to happen to our donors.

And I hear, I hear your passion in your voice, Cathy, and your emotion when you talk about this. What was that? Process like for you when they said, okay, here we go in. We go. It's, you know, as you said, the wham bam.

Kathy O'Toole: Yeah. Like, yeah, I, [00:17:00] I mean, I was very nervous going in, of course, because I wasn't, I mean, even though I'd been told you're still like, what's going on?

And you're awake for it. They give you meds, of course. So that, you know, the freezing it and everything. Um, and the nurse had said to me, just, um, just tap if you're. Yeah. Experiencing any pain. Well, I couldn't tap, but my, but my feet were flapping.

Okay, she needs more. She needs more like a top up, you know, so that happened a couple of times throughout because you have to be awake enough so that you can look this way that way. Move your eyes. And, you know, so they can get at the parts that they need. So, I mean, they all got kind of a laugh after that when they were telling me, because I kind of remembered, right?

But they were telling me that, but they said that that's very normal, but people very seldom do the tap tap, but it's. You know, usually the feet going back and forth, you know, so that, so that was kind

Candice Coghlan: of comical. [00:18:00] And so for someone who, like, I, I don't know much about that eye stem cell procedure, what did they actually do to you?

Or how did they explain it to you?

Amber Needham: Well, they were

Kathy O'Toole: taking stem, they were scraping the stem cells at 12 and 6. I didn't really get into the whole nitty gritty of everything that they were going to do because I thought that might scare me a little too much. But it was, it was just described that it was very minor in the fact of doing.

I mean, it took a little while because I had to get enough cells and whatnot. And I mean, I've regenerated my, my cells in like, no time at all. Like, they started regenerating

Amber Needham: immediately.

Candice Coghlan: And then the surgery process for you, Amber, what was that like for you? It

Amber Needham: was, um, like I was, I was getting a second chance.

I just, I felt in my heart that it was going to work and I, I didn't go into it fearing anything. I just, I was euphoric. [00:19:00] The thing that, um, probably brought me to tears was when Kathy was wheeled away from the, um, the joint room that we were in and she was wheeled away to go in. To the surgery room and she just grabbed my hand and she said, um, get ready.

She says, this is the first day of the rest of your sight life. And it's just like, no, I was, I was a bag of nerves, but I was just thinking, this is it. I'm getting a second chance. I was just looking forward to, um, getting my life back.

Candice Coghlan: And then when you woke up and you were told the surgery was a success, how did that feel?

Amber Needham: I was drugged up severely. Um, they, they gave me quite a bit of stuff. And so I was just, I was feeling. I was pretty happy because I had four [00:20:00] pieces in my eye, the two from Kathy, that 12 and six. And then I had two pieces of cadaver tissue, uh, at three and nine. And so my eye was stitched up and I was patched from forehead to chin as was Kathy.

Um, but I was higher neck height and, uh, and I think I was high on happy. And our, our good friend, um, took us back to our room, our hotel room. And, um, I don't remember much happened after that. I think we slept an awful lot to wear

off the drugs. Yeah. And, um, yeah, it was the most unbelievable day. I mean, the, uh, the feeling I had, uh, for Kathy was just.

Incredible. I was just overwhelmed by her generosity, her courage, her um, care. I was overwhelmed by it all. And, and, [00:21:00] and Dr. Chan too. Um, she says that I was a very fortunate, uh, patient to have such a, a great donor.

Candice Coghlan: And then how long after that surgery did you start to be able to see out of that eye again?

Amber Needham: Uh, it was very slow to start, um, but it was just different. My vision was just different. The fog that I had been seeing through for the two years prior didn't seem to be quite so thick. Um, and then of course I was on anti rejection medication, uh, that would be my concoction cocktail for the rest of my life.

And so my body was going through changes because of that and all the prednisone that I had to be on. I think when I was able to look at a cover of a book, which was one of my biggest goals, to be able to see clearly the cover of a book. And the day I was able to open it up and see a little of the text inside.

[00:22:00] That. That was probably a year after. Uh, and then it just got stronger. It got to the point where, um, seeing counting fingers was no longer and it was a piece of cake. Then I could see the large e up on the screen on in the mirror. I could see the E and that was huge celebration. Um, and then it just very slowly got better.

It got better and got better. And it, it did in my left eye. My vision did go back to 2020 I thought. I was seeing better, even though it was still 2020, the same as prior to my vision loss, but everything was just crisper and just, everything was clear. Now they did discover through all of this, the scratching is of my cornea.

I did have a cataract, so that was a procedure that I had to go back in for fairly quickly. Once that was taken out, it was just, I think I could see for [00:23:00] miles and, and the colors were bright and form. You know, I had missed that so much and, um, I vowed I would never ever take anything like that for granted again.

Kathy O'Toole: Annette Times wrote that, that time frame, like, I would say to her, you know, how's your sake today? And then she'd say whatever, then I'd say, well, I want those stem cells back then. Like, that was, that was a joke. That was a joke between us for, for quite some time.

Amber Needham: Yeah, you're doing good. I want him back.

Yeah, because after after the recipient and donor after we had gone to surgery, um, I mean, I just love this woman so much that that I couldn't get enough of her. And so we became very fast, close friends and we go walking together and, you know, again in business. Um, we would help each other in business. So yeah, we became really close and separable after that surgery.

Candice Coghlan: [00:24:00] So you were able to have your 2020 vision back and you know, life went back to what it was like prior to your incident. And how did things

Amber Needham: go for you? My stem cells are still working for me today. And what site I have is because of those stem cells. Because they were, um, Kathy had the best stem cells ever because my eyes have gone through so much.

I was back, you know, just ripping up the roads again in my car. I was traveling. I had gone to Hawaii. I was, I was, I was making sure that with my vision restored, I wasn't going to waste a nanosecond of my life. So I was probably two through almost maybe three years. Like that. And then, again, just like I said, [00:25:00] everything just.

It was so weird how it happened, but I had another freak incident just as freaky as the first one where I was in the kitchen and I was changing the bag inside my compost bucket and I was taking the bag out and so the bag wouldn't deploy down into the bucket. I had an elastic band around it, holding the bag in place.

But when I lifted that off the elastic band, moisture from the bucket flung in my eye with my glasses on and yeah, this little drop of moisture went in my eye and so I thought, Oh, well, okay, that's probably not great. So I went and rinsed my eye out and put my normal drops in and just carried on. Didn't think anything else of it, you know, continue to change the bag out of the bucket and carry on with my.

making dinner. [00:26:00] And, um, it was probably six weeks or so. And I was in between appointments with Dr. Chan. I started to notice things going really weird. Uh, again, almost like it had in the very beginning. Where my vision started to get very, very cloudy and I couldn't focus and everything looked far away. So I called Dr.

Chan and I said, okay, I don't see you for another month, but, um, this is what's happening. So she had me in right away. And unfortunately, that droplet of

moisture was a very invasive fungal growth. And that fungal growth had invaded. My cornea of my transplant. I so, um, very quickly, I was going right back to ground zero.

I was starting all over again. And, um, I'm here [00:27:00] today and what site I have today is because of the strength and the quality of Kathy stem cells and the fact that I never rejected them and, um, they, they were very weakened with all the treatment that had to go on. Thank At that time, um, but we were able to eradicate the fungal growth as quickly as possible, which probably wasn't quick enough for Dr Chan.

Um, and it did end up causing permanent damage in in my eye where again, I'm, I don't have the site I did have. I mean, the 2020 was gone the minute the moisture went in my eye. Um, but, um, you know, I do, what I do have is because of those stem cells, they, they did end up surviving, which even shocked Dr.

Candice Coghlan: Chan.

You know, everything that you've been through, you've taken [00:28:00] a lot of these difficult situations and these uphill battles, and you've stayed so positive. Through all of it and turned a lot of what you've been through into learnings for other people. Can you tell us a little bit about your book and your passion for supporting the eye bank and the work that Dr.

Chan

Amber Needham: does? Absolutely. Dr. Chan is somebody who I hold in such high regard because of her expertise and what she had done for me. So, when I had lost my sight the second time, I just resigned to the idea that, okay, this is the way it's supposed to be. If I'm supposed to be blind, then what quality of life can I have and how can this, how can I have it, um, where others can learn from it.

And, uh, so the [00:29:00] idea of the book and, and really my book, The Blind Girl Sees, Was really more started off as therapy for me as, um, helping me keep myself in positive thoughts and keep moving forward and finding a purpose and a reason for all of this. And then the book just morphed and got a life of its own.

And there were times when I didn't think it was me writing it. It was just, it just came out of me. I don't have any experience. Um, you know, writing a book or,

or anything. So, I mean, it just poured out of me and because I wanted to give back and I decided that the book once published that all the royalties would go towards something that I had eat, had it easy, which was finding a donor, right?

It was very, very simple for me. That is not the case for most. So I talked to Dr. Chan [00:30:00] and she suggested, you know, a stem cell donor registry, very similar to bone marrow registry. And I thought that was fabulous because then the recipients, you know, can have a little bit of the stress relieved knowing that there's a bank of potential stem cells there for So once I locked on to that idea, it was Full steam ahead.

I was going to make sure that that I did what I could. So the book became published and and then it was the, um, the tandem right for site. I wanted to take it one step farther because I just knew that, you know, um, if I could get out there and talk to people and promote the book that I could, I could get donations.

So, yeah, so the tandem ride for site, um, was my, my second big project.

Candice Coghlan: Everything that you've, you've been through, um, all that, that you've done [00:31:00] now to give back as well. I'm wondering if there's anything that you would want to tell other people who are going through difficult situations, whether it is a health.

Experience or or something else. Is there something that you would want

Amber Needham: to tell them? Yes, absolutely. As with the message in my book, the overall message is we all have something in our life that sets us back. Um, and the sooner we accept it and embrace it and then try to turn it into something that is a gift.

Rather than a curse, because somebody else is going through it too. And it would be nice if they knew that there was, there was help out there, that there was people that understood. You can't change it. You can't change it. So the best thing you can do is [00:32:00] accept it and, and then, um, have a purpose in helping others.

Because of

Candice Coghlan: it and Kathy, you know, being through this whole process and becoming a donor. I think some people would love to be able to support their friends and their family the way that you have, but they might have fear

around this situation. Um, would there be something that you would like to tell people who might be considering either stem cell donation or blood donation or even, uh, solid organ donation from your experience, you would want to share to them.

Yeah, if you're

Kathy O'Toole: thinking about doing it, do your research, ask lots of questions. Um, fill out the donor, even if it turns out that you that it's not for you, fill it out, go through the process, look to the future and just, just go for it. It's so rewarding on both sides, [00:33:00] you know, and yeah, it's very rewarding and I have to say that Amber is the most positive, outgoing, stubborn person I have ever met.

And she is and it's that, and it's that tenacity in her. I'm sure that has gotten her through. I mean, obviously she had her down times. I've seen her in bad moods, but not terribly bad moods, but I know darn well, but she's gone home and she's pulled the rise out and but she always. She always put her best step forward.

She was very positive and I often said to her, like when she was saying, no, I can do this. I don't need help. I says, look, we all need a helping hand sometimes in one way or another. So look at it in a giving way that it's not like, oh my gosh, I could never do that. You know what? You can do it. You put your mind to it and you can do it.

Incredible.

Candice Coghlan: Has this [00:34:00] journey changed your life in any way?

Amber Needham: Yeah, I

Kathy O'Toole: think it has, even though, like, I am a nurse and I have seen all kinds, good, bad and the worst, um, but this is a personal, um, so rewarding. I'm so more, um, aware of people that may need help. I think I even tend to be more helpful. It's put it in, it's put it in a whole different perspective

Candice Coghlan: for me.

Welcome, Dr. Chan. Dr. Chan is the associate professor at the University of Toronto, medical director of the Eye Bank of Canada, the Ontario division, and is in the ophthalmology department at Toronto Western Hospital. And Dr. Chan was actually also included in the 2021 ophthalmologist power list. That is really

remarkable, recognizing the top 100 most influential female figures in ophthalmology internationally.

So we [00:35:00] are so incredibly grateful for you to be here with us today. Thank you so much for joining us. Thanks for having me. And Amber has quite the connection with you, Dr. Chan, as well. Um, Amber, is there anything that you would like to say to introduce this remarkable woman?

Amber Needham: Well, very much that she, Dr.

Chan, is remarkable. She... Has, um, there's, oh, I don't even know where to begin because I just, I just hold, uh, Dr. Chan in such high regard, uh, along with her, uh, uh, credentials and, uh, it's the person that I know that she is, uh, outside of her doctorate, um, how she treats her patients is un believable and outstanding.

I feel blessed every day that I was, um, referred to by Dr. Mather to Dr. Chan. I thank my stars every single day. [00:36:00]

Dr. Clara Chan: Well, Amber, Amber is a very remarkable patient as well. So I think it's a, it's a testament to her perseverance and. You know, it's, it's always, it's always nice to see patients try to maintain positivity.

So, um, I think it's always inspirational when we see Amber come into the clinic and I get to tell our fellows and residents about her story and it's very moving and, you know, it's a lesson in itself on just humanity and the strength of, of a patient.

Candice Coghlan: So, Dr. Chan, I'm wondering if you can tell us a little bit about yourself outside of, um, potentially who you are as an ophthalmologist.

Dr. Clara Chan: Well, um, so I have, I wear multiple hats, uh, certainly just the clinical side. There's also the research side. Um, the way our practices are set up, basically most of our research and preparation for lectures and teaching are done after hours. Um, and so there's that aspect, [00:37:00] um, in terms of teaching and mentoring our ophthalmologists and cornea specialists internationally who come to train with us.

Um, we really become an extended family. So, you know, there's people from Australia that we've trained or South America. Um, that sort of text me at any given time of day, middle of the night because of the time differences. Uh, so we're always, it's nice, we're always connected that way. Um, personally, I'm a

mom, so my job after work, I go home and put on that job at, and that's also keeps me busy.

Um, yeah, so. Our lives are very full and it's nice to kind of keep a balance that way to not only help our patients and be able to do research and advance sort of the greater knowledge and impact that we can have to more than just the patients we see on a daily basis, but then also the teaching side. I really enjoy and.

Being able to train the international, um, [00:38:00] fellows who come and then they go back to their home countries and become leaders in the field and be able to share their skills that they've learned with us, um, in their home countries. It's really nice to see as well.

Candice Coghlan: So going back to. Um, your work and your research, what led you to specialize in, in cornea, cataract and refractive surgery?

Dr. Clara Chan: So it's amazing that the little eyeball has probably about six, seven different subspecialty areas to it. Uh, the cornea is the clear dome that covers the eye in the front. And so. As a resident or in training, I always just liked being able to see look at them through the machine, see the patient's eyes, and it would be a very spot diagnosis.

And just by looking at it, we kind of knew, okay, what could we do to fix it? Um, it didn't necessarily require. Multiple, multiple investigations in order [00:39:00] to figure out what the puzzle was, or, you know, what is the diagnosis and what is this caused by? Um, so I did enjoy that kind of rapid fire, quick, um, diagnosis aspect of it.

And then the interventions that we have, um, you know, many subspecialties have maybe like 4 or 5 procedures that they do for the conditions. And I would say in cornea, we probably have maybe. 2530 procedures that we are able to perform, um, to manage the various ocular surface and corneal problems and, you know, front of the eye diseases that exist.

And so I really liked being able to just have this big tool belt of, of, uh, treatments to be able to offer patients. And every day is different. There's variety. Um, and overall patients have reasonably good outcomes, uh, and have, you know, positive results from what we're able to help them with

Amber Needham: surgically.

Candice Coghlan: What are some of those therapies [00:40:00] and, and treatments that are performed by you and your team?

Dr. Clara Chan: Uh, so cataracts is the bread and butter for all ophthalmologists. So, you know, that's just an aging change of the lens inside the eye. And so we can take that out and replace it with a clear lens implant, um, and no matter what ocular disease you have.

you'll probably end up with a cataract. So most of us have to be able to do that very proficiently. On the surface of the cornea, there can be just lumps and bumps, we call them. So people who have like excessive sun damage, they can develop scar tissue called a pterygium that we can remove. And prevent it from growing back.

Um, you can have little like calluses that grow on the cornea called Salsman nodules that we can scrape. Um, if patients have had chemical injuries or thermal injuries, uh, various sort of, you know, medical, uh, medication damage to the eye surface, they can develop little stem cell deficiencies such as an amber story, um, or drug reactions.

Uh, [00:41:00] or various allergies or even people who have bad like a topic disease. They have eczema. They have allergies, runny nose, they have chronic inflammation. Basically, anytime the eyes are red, it can be causing some sort of damage to the eye surface. And so you can do procedures or use adjunctive therapies, like amniotic membrane to try to rehabilitate the surface.

Um, if patients develop calcium buildup on their eye surface, we can kind of leach away that excess calcium buildup with chemical treatments. Um, and then, you know, you move to the actual cornea itself, which is the clear, transparent piece of tissue. Um, and that aspect requires. the cornea to be clear in order for good vision.

So the cornea has five layers and basically each layer can be individually transplanted. And so you're talking about half a millimeter of tissue that can be sliced and diced and Operated on. Um, and this is really in the last sort of 10 years where we've [00:42:00] had this exponential advancement in technology and instrumentation and different, you know, techniques that have been developed to allow us to really target which layer of the cornea requires fixing, uh, in order to fix it.

And so in terms of transplants, it used to be that you would, no matter what condition, you have to cut away the whole cornea. And then so on a new one

from a donor, but now we can peel away the back layer and just replace 10 microns of it. We can peel away the back layer, but replace it with about 50 to 90 microns of tissue.

Uh, we can remove from the top down. We can remove 80, 90%. And keep the patient's back layer and just replace that anterior layer, uh, we can do different sizes. We can use laser to help us with cutting. Um, so, you know, there's just so many different things that we can do, um, that's much more targeted and I would say, like, the newest kind of up and coming exciting technology is actually cellular [00:43:00] injection therapy.

So right now we depend on donor, the Uh, tissue. So one donor cornea transplanted to one recipient. Uh, in the future, as we ramp up sort of advancements in cellular technology, we have one cornea where the cells could be expanded to supply enough treatment material for like 200 patients. So it's, um, it's really exciting, uh, technology.

And I think we hopefully will be one of the sites in the coming year to be in a study trial that can actually, you know, be a part of, of advancing the cellular technology.

Candice Coghlan: So this brings me to my next question, which could be impossible for you to answer, but what does an average day look like in your role?

Dr. Clara Chan: Yeah, so there's no day that's exactly the same. We either have clinic days or minor procedure days or major operating room days. So, on our, you know, [00:44:00] surgical days, we can either do a list of 20 cataracts, or we can do a list of 5 transplants, um, or we have you know, 15 minor procedures of like the lumps and bumps kind of in and out topical anesthetic type cases that are, that are kind of light and fun.

And then on our major kind of complex days, uh, maybe we spend a whole morning doing a living donor to a, um, live recipient stem cell transplant, for example. So, um, it depends on the day. And then on our clinic days, we will see 60 to 70 patients. Uh, pretty routinely. Uh, and so it does rely on a big team of technicians and support staff.

Uh, certainly our cornea fellows and residents interact with the patients and, um, I'm supervising them and it's, uh, it's a big team, but we're able to provide sort of care to all the most extreme [00:45:00] forms of, of diseases of the front of the eye. Uh, where many places aren't able to provide that kind of care.

Candice Coghlan: So you've talked about transplant a couple times, and of course, um, Amber has shared her amazing story and, and Kathy has as well. For, for those of us who don't know, can you explain a little bit more about what Stevens Johnson syndrome is and how that, how that affects the eye? Sure. So

Dr. Clara Chan: Stevens Johnson syndrome is a condition that's Essentially a severe allergic immune disease where the whole body can experience like third degree burns and every mucous membrane can also slough off and require healing.

So patients are in the burn unit often if they're severe or the intensive care unit. because essentially they're like a burn victim. And so their, uh, internal oral mucus membrane sloughs, their esophagus, everything that's mucus membrane, [00:46:00] including the ocular surface, which is actually mostly made up of mucus membrane sloughs off.

the skin on their bodies slough off. They're at high risk for infections. Uh, and this can last until the immune system sort of just is able to calm down and, and recover from that severe allergic reaction. Uh, and the tricky thing with, with the Stevens Johnson patients is that, that hit, that initial hit that they get with the severe inflammation, it doesn't just stop when these patients have had a severe reaction like this.

Forever their mucous membranes are always inflamed and so it's just like trying to You know, plant new seeds in an area that's chronically on fire. It's almost impossible. Um, and then not only that is that the damage done from the initial reaction, uh, changes the whole ocular environment. So most [00:47:00] patients, their eyes, if.

They get an infection, they're able to clear it on their own. Um, a patient who's had Stevens Johnson, if they get an infection in the eye, it's often somewhat of a bad infection, like a fungus. That's pretty rare to have in, in Canada. Um, you know, it's, it's harder to get rid of, it's harder to treat. Um, so when they do get infections and other problems, it's often more severe.

Candice Coghlan: And Amber talked to us about her situation and how she was finally sent your way. And you brought up the topic of a stem cell donor for her eye. What is the process like for finding a compatible? stem cell donor for, for their eyes. Is it difficult to find a match for people? So

Dr. Clara Chan: most of the time the match would be either a sibling or a parent.

So you need to have blood type compatibility and also ideally that you have protein [00:48:00] compatibility. So on all our tissues there's something called HLA proteins. And so the more you have in common than the The less chance of rejection if the recipient and the and the donor are blood siblings, then they have the highest chance of being 100% match.

Parents would have like a 50% chance match. It is very rare. And if I think Kathy and Amber might be the only. friend to friend, uh, non related, uh, recipient donor, uh, case that, that I know of. So, um, other than that, we would use deceased donor tissue. So, uh, but for living donors, um, it's, uh, it's a very unique relationship that we see before us.

So, um, but yeah, ideally, we use a living donor because the tissue quality is obviously more fresh. Uh, we will use it. deceased donor tissue if there's no available living donor or the patient doesn't want to inconvenience anyone. [00:49:00] So then we would consider using a deceased donor. Uh, so with the deceased donor, most of the time we're able to get the blood type match, but we're unable to obviously match all the other proteins because, um, when they're, it's just really difficult to find a random person to actually match all those multiple other proteins.

Candice Coghlan: So thinking about that, um, I'm guessing then the wait time similar to with solid organs would be much, much longer for somebody to wait for a deceased stem cell donor than it would be to find a living donor. for this process.

Dr. Clara Chan: Yeah, if they have a related living donor, then we can do the screening much easier for a deceased donor.

It takes longer because first of all, we would want to find someone who's a type o donor because that's a universal donor. They they won't react with whichever patients blood type that there is. Some patients are already at higher risk [00:50:00] for the fiasco. Rejecting because they've had blood transfusions, or perhaps they've actually anyone who has given birth like they've been exposed to the fetuses protein.

So they're at higher risk because they've been exposed to foreign somewhat material. So, so finding the deceased donors are more challenging.

Amber Needham: And

Candice Coghlan: so in, in Amber's situation, she had Kathy donate stem cells. And then she was explaining to me that she also had some deceased donor tissues as well. Is that very common to do for people?

So in

Dr. Clara Chan: Stevens Johnson cases, yes, it is because of that chronic inflammation and the severe disease status that patients present with when you take tissue from a living donor. We can't take all their stem cells because then they would develop eye problems. So studies have shown that as long as you maintain 50% of your own native stem cells, then your [00:51:00] eyes are fine.

Um, and then in Amber's specific case, because she had sort of very diffuse disease and the eyes were chronically inflamed. If you only transplant six clock hours of tissue, the scarring can still come back across the cornea from the areas that had no stem cells because the stem cells basically function as like barriers.

To blood vessels growing in and the cornea is supposed to be transparent. It's not supposed to have blood vessels. If it has blood vessels, that's what causes the problems with vision. Um, so we wanted to really make sure that we got 360 degrees of coverage. Um, and we didn't want to, we wanted to keep. the donor's eye, like second eye as like a spare.

We didn't want to need to take tissue from both eyes. So, uh, we often will kind of share, like do half of the cells from a living donor and then half the cells from a deceased donor. Um, and that gives us the 360 degrees of coverage, uh, to [00:52:00] hopefully sort of barricade the abnormal stem cells and the blood vessels from growing back.

Amber Needham: Fascinating.

Candice Coghlan: How common are living eye stem donors? This may be a difficult question to answer, but how often do you see living donors coming forward?

Dr. Clara Chan: So for patients who have a sibling or a parent, uh, usually it's, it's pretty good. Uh, so actually I would say most of the patients, they, we can use their good eye to donate to their bad eye.

So most of the stem cell disease, diseases that we see, the cause of it is usually like one sided, which is actually great because then for sure, you know, that they're not going to reject their own tissue from their good eye. And then also,

um, the other conditions that we often will see stem cell disease come from are people who wear contact lenses.

For, you know, whatever reason, the contact lenses reacted poorly in their eyes and they developed the scar tissue. [00:53:00] But yeah, so most, most commonly would be an autograft, meaning it's from the patient's own good eye. And then the next common would be the deceased donor tissue, probably, because it's just hard to find necessarily agreeable relatives.

Siblings, friends, it's very rare to, it's actually, it's a big, it's a big call, right?

Candice Coghlan: Like Kathy actually was, was saying, uh, you know, some people said, said to you, Kathy, like, Oh my goodness, your eye.

Kathy O'Toole: Exactly.

Dr. Clara Chan: Yeah. And I mean, when we draw it out and we show them videos and pictures, like it's, it's literally just almost taking like a little mole off.

So in terms of surface area, it's like teeny tiny. But I think. Just people get a little squeamish around

Amber Needham: eyeballs.

Candice Coghlan: So, Amber talked a little bit about the Eye Bank of Canada. I'm wondering if you can tell us what the Eye [00:54:00] Bank is.

Dr. Clara Chan: Sure. Uh, so the eye bank is where all the ocular tissue gets processed, and so it's not just corneas that are used, like every piece of the eyeball can become useful, and if it's not useful for, uh, donation and use in a recipient, uh, it's used for research and training, but the corneas used for transplant, the sclera, which is the white part of the eye, can be used in glaucoma surgeries, even the corneas.

Um, the lens inside the eye, um, you can't really use it again in a, in a recipient, but we, we can do studies with it. Um, so, yeah, I mean, it's the whole eyeballs put to good use. And so we have technicians who evaluate the eyes, uh, we work very closely with. the Trillium Gift of Life program. So they have the team of recovery specialists and technicians who go out and actually recover the eyes.

Um, and then we'll come to [00:55:00] the eye bank of Canada, Ontario division. Uh, so there's a whole process that goes into, uh, processing the tissue and preparing it for use, um, in live patients.

Candice Coghlan: Another question for you. Amber talked about her passion and her fundraising and all of the amazing things that she has been doing and talking about the potential for this eye stem cell registry.

Um, there's currently a stem cell donor registry that exists through Canadian blood services. And. There's no stem cell registry for, for eye donation. Is, is that

Dr. Clara Chan: correct? Right. So right now the, uh, what a registry is would be like a list of donors who are, who would be willing to donate their stem cells on their eyes for potential patients who are in need.

Uh, so say Kathy did not know Amber, but wanted to [00:56:00] become a donor. She could potentially. get in touch with our stem cell coordinator and say, look, if anyone ever has this condition, I'm willing to donate for, for them. But formally speaking, we don't really have just an ocular registry. Um, and once again, it is challenging because to even just ask a friend, not a relative to make that sacrifice for you, it's a big ask.

So to do it for a stranger would be another leap of faith. You

Candice Coghlan: talked a little bit about some of the amazing, uh, initiatives that are, are happening at UHN and, um, some of the research that you're doing. Can you talk to talk about, uh, your research interests and, and what you're currently working

Dr. Clara Chan: on? Sure.

Um, one of my interests is actually like wound healing and how the eye surface, uh, is able to repair itself. So, um, I mean, the nice thing is. [00:57:00] The surface of the eye repairs itself typically very quickly and very well the surface skin layer, which is the epithelial layer, which is where the stem cell disease exists that layer.

If you were to develop a corneal abrasion within 48 hours, usually it has already started to heal over itself. And it's because of these stem cells that create that ability to heal. So these are in like normal eyes. So the question is in abnormal

eyes, why can it not heal in the same rapid way? So one of the reasons is stem cell problems.

Another reason is if patients have abnormal nerve sensation. So diabetics. People who have had thermal injuries, chemical injuries, severe infections, their, um, nerves in their cornea no longer can feel. So if you think of a diabetic who gets like a foot ulcer, they can't tell that they have a foot ulcer problem.

Um, and they can get infections and it just gets really bad quick and they need an [00:58:00] amputation. So, similar with the eye, if patients who are diabetic, for example, they can't feel their eye, then the brain is unable to recognize that there's damage to the eye surface. And so, someone who has what's called neurotrophic disease, so that's where the nerves are shrunken, trophic, um, then their tear quality is poor.

They don't produce enough tears. Their tears don't have the proper growth factors and healing factors within it. Um, and then they develop these scratches on the surface of their eye that don't heal properly. Um, so the nerve problem is another factor. And then you've got sort of, um, like physical anatomical abnormalities that can be on, that can be problematic as well that limits the healing of the eye surface.

And so with, with all these different problems, the question is, what can we use to try to heal the surface of the eye better. Um, and we have products like amniotic [00:59:00] membrane, which is what it sounds like. It's the wrapping of a baby and there's different forms of it. So there's commercial products where it's been processed and sterilized and dehydrated.

Um, and then also we have fresh frozen. So there's a donor usually once a year that will donate their amniotic membrane after they've given birth. Uh, and when patients have acute Stevens Johnson syndrome, we now know that if you can put amniotic membrane onto their eye surface and cover every single layer and every single part of the ocular surface mucus membrane that's exposed with amniotic membrane within that first week, They can actually avoid a lot of the stem cell late damage changes that occur.

Amber Needham: All

Candice Coghlan: of this is, is remarkable. I didn't know. All of the incredible things that can, that can be supported. I'm wondering, uh, Kathy or Amber, do you have any questions for Dr. [01:00:00] Chan?

Kathy O'Toole: So I do have a question because I've already been a donor to Amber. Could I still be a donor to somebody

Dr. Clara Chan: else? Yeah, so I would, um, we wouldn't take from the eye that served as a donor for Amber's eye, but this, but your second eyes could certainly serve as a donor to another recipient.

Kathy O'Toole: Okay, so if Amber needed another stem cell, I could still donate?

Dr. Clara Chan: That's right. So we would use the second eye as the source. Okay. Yeah.

Candice Coghlan: I'm wondering if there is anything that I did not ask you today that you think is important for people

Dr. Clara Chan: to know. Actually, there is one aspect that I forgot to mention, which I think is pretty exciting, is that We have a trial right now ongoing where, uh, in patients where they can typically be an autograph donor, like where they donate from their good eye to their bad eye, uh, what we can do is actually, instead of [01:01:00] taking 6 o'clock hours, we would only take maybe 2 or 3 o'clock hours and we would send those stem cells to a lab in, uh, Quebec.

And they would actually expand those cells onto a piece of amniotic membrane, and then they would send it then back to us, where instead of just, you know, 3 o'clock hours of tissue, we get a whole 9 millimeter disc of cells. It's like a sheet, and we could sew that onto their eye surface, um, to be, yeah. So that's like a cell, another cell based type of therapy that, uh, we are part of a trial, um, to be able to offer that.

So that would require, though, for a patient to have enough normal cells that we could safely harvest at least about 3 o'clock hours of cells to then send to the lab in Quebec to expand to the, um, 9mm disc. That is [01:02:00] so cool.

Candice Coghlan: Thank you so much to all three of you for joining me today. Amber and Kathy, I'm so grateful that we've connected and you've shared your journeys and, um, thank you for being so vulnerable and open with us today.

We will definitely include a link as well that you can check out Amber's book because, uh, if it's anything like our conversation today, everyone should definitely buy that book and like Kathy live in that book.

Amber Needham: Thank you. And you too, Candace. Thank you for having us.
And

Candice Coghlan: Dr. Chan, thank you so much for sharing your expertise.

I've learned so much in this short amount of time. And I know that listeners will also really appreciate getting to hear all of your remarkable work and your dedication to your patients too.

Dr. Clara Chan: Thanks for this opportunity.

Candice Coghlan: Thank you all so much. We hope you enjoyed this episode of the Living Transplant podcast.

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