Deborah:

Hi everyone. Deborah Gold here. Executive Director of BALANCE. Before we begin I just wanted to hop on and say a huge thank you to all of our donors in 2021. Support from our donors makes a real difference in the lives of our clients, and it includes initiatives like this podcast which is aimed at helping people with sight loss everywhere in the world. We hope you enjoy listening as much as we enjoy making these shows. If you do, please consider making a donation. The link can be found in our show notes. Happy holidays, and enjoy the episode.

Ramya:

Welcome to Living Blind. I'm Ramya Amuthan your guest host for the next three episodes of this podcast. The Living Blind podcast explores the perspectives and lived experiences of people with lower, no vision and delves into the. Challenges and real life strategies that they have for living life to the fullest.

This is the start to a three part series on the intersections of blindness and other lived experiences and identities. This podcast is brought to you by BALANCE for Blind Adults located in Toronto, Canada. And this season of Living Blind is sponsored by accessible media, Inc. A bit about me to begin with I'm the co-host of Kelly and company.

This is the live afternoon show on AMI audio, and we focus on everything from lifestyle to arts, to culture and entertainment. I'm also the host of AMI. Audio is new podcast called AMI audio book review. And this is a weekly chat where we talk all things, audio book. One of my friends and a very incredible member of the blind and low vision community is Windy Ho Li.

And we're going to get to know her a little bit on today's episode of Living Blind. So Windy, welcome to Living Blind. I'm doing very well. That's great. And I'm really looking forward to chatting with you because we've known each other for several years now and came into each other's contexts in different ways.

Ramya: And now I've gotten to know you a little bit, but I want our

listeners to know a little bit about you and the things that you do, the work that you're up to. So you started, let's talk about your vision. First. You started losing your vision at age 17. Can

you tell us first what your diagnosis is?

Windy: Well, my diagnosis is limbo stem cells deficiency, which is, um,

a damaged from a contact lens using, and it's a scar tissue on the cornea that affected the visions and later on it bulds up and I had a couple of surgeries on and off. And right now it's stable,

but I'm legally blind.

Ramya: So before 17, did you have moments or times in your life or

other kinds of checkups where you knew that this may be a

problem or was it all very new as a teenager?

Windy: It's all very new. All of a sudden in one day I lost my, I lost my

sight on the left eye.

Ramya: Okay. And how about your right eye?

Windy: My right eye started losing it a year later when I was still able to

drive and all that suddenly I started realizing, oh, my right eye

started declining with my sight. Then I went to my

ophthalmologist again and ask her it's anything related to my

left eye. And that's when my life turned all around.

Ramya: Yeah, Yeah, absolutely. So I'm going to go back to something

you said, you said that you were driving, so you're like here in Canada, we drive at 16, right. Or at least that was the thing. So you'd been driving for like about a year or more than that before

you started realizing, oh, my life is changing dressing.

Windy: Yeah, I've been driving. I got my license when I'm completely

fully sighted. And then I believe it was half a year later I lost my sight in one eye. However, I would still drive with my other eye, right? Cause it's legal to drive with one eye only. Until I lost my

other eye sight.

Ramya:

Wow. This is a big point because, um, a lot of us who are blind or low vision, or have had to go through significant vision loss, really take driving as some huge piece of information. It's a huge thing that so many of us either wish we can do or had done at one point that we miss so much, it makes such a, a crucial difference in our lives, not to be able to drive anymore for anyone who has. Um, so talk about your vision since then your journey. Uh, you talked about like having a few surgeries done what's happened between 17 and now?

Windy:

Oh a lot have happened. I had several surgery, uh, field them are, um, some trends, uh, transplant, uh, getting, uh, stem cells to transplant to the eye and, and, and then. It's been awhile. I think, um, I would say a epithelium transplant. That's what I did. And just getting some donors, have an epithelium and place that in my, in my cornea so that, that could help me with my vision a little bit. And it did increase my eyesight quite a bit, um, from probably like 2,400 to 2300. 2200 fluctuate there. That that's the number that fluctuates for a few years. And I also did like a buccal mucosa epithelium transplant. It's been like 10 years that I have done that surgery and it's basically, um, getting some, um, cells from my own mouth to, to regenerate it and put it in my eye and hopefully that will help with my stem cells because that's what my diagnosis is, limbo stem cells deficiency. Yeah. And then another one that I, I forgot already what it is, but it's, it's all about helping the epi... epithelium to be healthier again so that I can, um, maybe stabilize my vision.

Ramya:

For a lot of people, um, having the opportunity to "A" be diagnosed, right? To know what your eye condition is and to know, okay, this is what's actually happening is a huge shift in attitude, uh, because there are people out there who don't know what their eye conditions are and, um, I have some friends who, you know, they go back and they have regular eye visits with optometrists ophthalmologist, um, all kinds of medical

Ramya: specialists, and still can't be told what exactly their eye condition is.

> But the opposite side is this where you have. Several different things that you're working with. So many surgeries, um, some surgeries that have helped some not so much. And you've been doing it for years. Like throughout your twenties, you mentioned a decades worth at least of surgeries. What keeps you going for the strength in terms of like dealing with the pain, the medical visits, uh, all of that.

Windy: Well for me, um, my faith really helped my life to know that there's hope in life and what I have it's temporary and one day it's going to be different and I'm going to be, um, better again. But meanwhile, when I'm here, you know, uh, there's still hope, right? There's still other things opportunity out there for me to grow.

> And, um, being able to know BALANCE for Blind Adults three years ago was a blessing to me and, um, overcominglots of obstacle that I come across on the street being able to use the cane and just, um, finding my independency again. That's that's um, that's where my focus is on now. That I can bless others with the gift that I have with the skills that I have learned.

Yeah, absolutely. And for a lot of, um, the time that you've been going through surgeries and hoping for, um, maybe some vision recovery, you've also been learning how to be a person with low vision. Is that accurate?

Oh, yeah, for sure. Um, I guess I can always compare myself being sighted and visually impaired um, because during the 13, 14 years, I also got opportunity to have like a piece of contact lens to put in my eye that I can see 20/30 again with my sight and just being back and forth with legally blind and being able to see, again, really, um, as a learning curve for me and I do have, um, adaptive technology that I learned to continue to be connected to the world and society.

Ramya:

Windy:

Ramya:

Fantastic, Windy. I want to ask you one more question in regards to your, uh, eye condition. You mentioned chronic pain, and I want to know, because to me it's really, uh, one thing to have low vision, and it's another thing to all the time be reminded of it because of the pain that you're going through from your vision condition. So how does that play in your day to day life in your, um, your concept of hope and, and trying to be, you know, courageous through it all. Uh, but still having to deal with chronic pain.

Windy:

I guess dealing with chronic pain gets it's tough. It's definitely a not easy curve to, to go through. However, I tried my best to, to distract myself with positive energy that that, that can put into my life, whether it's building friendship and connecting with uh people that come across vision loss as well, or people with other disability and to encourage each other and to be accountable, um, and also find the times of stillness and rest. Right. And that's very important to recharge and, and to be, um, To, to be able to get my mind off my, um, eyes a little bit and focus on to something else and then come back to it the next day and know that there's still hope in life. And there's still joy in life. Despite the fact that, yeah, I'm pain, I'm in pain, I'm in pain, but I'll do my best, um, to, to rest and come back to the next day to work on it again.

Ramya:

What's your support system, like in dealing with that?

Windy:

Well, I have a lot of, uh, church community friends that I connect with as well as, um, quite a bit of, uh, people that walk with me also with low vision and I'm a Cantonese speaker um, so I do have, um, that part of, uh, my organizations that I was doing a lot of volunteer work with, um, that has sight loss with, with, um, Cantonese speaking. So that's also part of my support group.

Ramya:

Yeah. Uh, it's really important to find community. And there's always a, a bit of me that thinks, you know, no one will understand exactly what you're going through. Everyone's journey is very, very individual. We're all on our own walks of life. And like you said, we need to take the time out for stillness, for quiet meditation, um, to be able to come to terms with ourselves, right? Our bodies, our minds, and then there's nothing we can do without the help of others. Uh, and then you're, you're talking about that with your communities, your friends, your family.

Ramya:

Okay. I want to talk to you a little bit about, um, your journey and how that plays into your value systems. So you do a lot of work. You talked about being a Cantonese speaker and having some community support from the low vision community. Do you have anything specific to say on diversity and what that plays in your journey?

Windy:

Yeah. So basically as a person who, who, um, English is their second language, we often come across a lot of barrier, even in the mainstream, um, mainstream platform that we come across with, uh, with BALANCE or with other support system. We might not. Uh, be able to speak the language. So, um, what we do is we have, um, our support system and we speak the same language. So if we come across anything that we do not understand and how to use technology, then there will be workshops that the organization will host. However, if, if we needed some instructors and we'll try our best to find a translator and to connect with either BALANCE or, um, CNIB, um, to help with, with our, our, um, mobility.

Ramya:

So do you find that, um, in knowing all these different people, there's a lot that you can share and relate to, or are there other things that make you feel like you can find community in these people?

Windy:

I guess in terms of relating to others, for sure. Um, like we have the same belief and the faith at the same time, um, we speak the same language and the mother tongue is in Cantonese. So we came from either Hong Kong or China, that's where we're from. And yeah, of course, when we're here in Toronto, often we get discriminated because of our skin color or our a language barrier. So we'll share those experience that we have and try to tackle it and see if there's other strategy that we can overcome the obstacle that we face.

Ramya:

What's the significance for you in having this bunch of people who are either also low vision like you, or going through some kind of, um, vision loss or blindness versus the general Cantonese community in Toronto?

Windy:

Well, we'll say for example, using adaptive of technology, being able to connect with a group of people that has visually impairment and using, um, and having cantonese as their primary language, some of us doesn't even know how to use English or read English. So therefore the support system could help us with adaptive technology, knowing how to change our setting in our phones so that the phone will allow us to, um, read the, the content in the phone for us and in our own mother tie in Cantonese or Mandarin. So that we can still be independent and connect to this society. I think that's really one of them that's very crucial. And also how do we connect with the mainstream events that's happening through CNIB? So we would communicate and have our own little, um, email lists or a group chat that we have, or, um, workshops that we organize to know more about ODSP or other resources out there so that we can still be connected and can contribute to this to the community.

Ramya:

So what I'm hearing is it feels like a very, very close knit, um, community or a group of people when you have, you know, these kinds of email lists or, um, you're talking to each other consistently on how you can contribute out there. And how do you guys make sure to open up the space and invite other people in? You know, is there, is there some kind of outreach that you do for other, uh, low vision or blind people of Cantonese background who may be looking for you?

Windy:

Mhm. So, uh, our, our organization, Joy Beyond Vision community, we do send out emails. We are right now trying to even send out emails to, um, the CCB or other organization out there so that, uh, even on the radio Cantonese, a radio channel to connect with other people in Toronto. So that when they listened to the radio or the newspaper, they, they would, um, know that we're here and this is the support system and where we welcome everybody to join.

Ramya:

That's so amazing. I, I always am fascinated by these little, um, niche parts of the blind community in Toronto, because I find that the Toronto blind community is very, very out there. You know, you can hear us, you can see us we're all over the place. Um, but then when we tap into these specific ways that people are finding each other, it's so incredible and it never ceases to amaze me.

So Windy you talked about valuing the contributions that you put out there, right? Either as, um, as work or a volunteer, or just to make sure that people can hear what you're doing and you're giving people tips on technology and things like that. How important is that for you to not just, I guess, in an opposite, you know, sit at home and do nothing or feel like your life is not worth it?

Windy:

Think by encouraging others. It bring lighten up my day a lot. Right. Brings me joy to see other people grow at the same time so that I'm, we're all not alone in this. And that's very important. Um, that's what I do in my daily base, who just call each other up and check in on each other and just see if we need anything.

Right. And if there's help that we need we'll we'll connect and we'll try to encourage by words or by action.

Ramya:

You yourself are a very active person. Um, I know you through the Toronto ski hub and, uh, through there, I found out that you're very, very adventurous and love to do a lot of outdoorsy things. So can you talk to us about some of the hobbies and things that you love doing?

Windy:

Well, I grew up as a dancer. I love to dance. And then the top. Yeah. And on top, that's why I found out about Ski Hawk when I lost my sight. As I return back to Toronto. I found out what ski Hawk and that's how we met in Toronto, Ski Hawk. And I also love to tandem bike with my husband. So he's my captain he's my eyes. And, uh, I would say I'm, I'm an adventurous. I like to try everything. Um, hiking. I love hiking. So we went hiking in the fall. Just even if um, see as good, you know, my, my friends will give me all your descriptions of what the scenery are like, or just help me out a little bit and just to educate each other right? And it's, it's, it's continued to be exploring what's what's around here and I love to cook. That's another thing that I really love to do.

Ramya: So cool. What kind of dancing?

Windy:

Uh, I grew up doing ballet and then later on, I was trying out contemporary dance and jazz and little bit and salsa when I got married.

Yeah. That's a few things I do. Um, I love dancing. I would even like dance in a small little studio size that I live in, um, and still dance right now.

Windy:

It's amazing to know that there are parts of you that you, um, are kind of reluctant to let go of. You know, you talked about having driven once, and obviously that's not an option for you right now to be driving a car, but dancing is something that you had before you lost your vision, and it's still a huge part of your identity.

Ramya:

And I wanted to ask you, before we start wrapping up things, you mentioned faith a lot throughout our conversation. And you mentioned that, uh, hope is a huge thing for you. Um, and you also mentioned, you know, being really wrapped in the Cantonese, blind and low vision community and, and having that as a very great outlet for you.

Uh, but also how do you feel about stepping outside the blind community and making sure that you're still tapped into the world besides disability? You know, bringing yourself and your disability and your journey into the bigger, wider world and, and interacting with people that way.

Windy:

Um, I would say since I have, I have my two little dogs. Five pounds toy poodle. I would re I would put that into my community that I see every day in the neighborhood. Right. If they come to me and I can't see their face, I would explain to them, Hey, this is my condition that I have. If you see my little dogs, please help me out that something they're doing wrong, let me out and, uh, give me a heads up and be advocate. Right. And. Uh, allowed people to know my, my issue and my problem, and continue to find other, um, volunteer work that I can do to connect with, with, uh, with others and with my church community, even they're all sighted. Right? And, and keep educating them that's that's my whole, um, whole, whole aspect of my daily living is to share and care for others. And just not forget, even though I'm I have my disability, but I'm still capable and beyond capable to, to inspire others around me.

Ramya:

You're here. So much to offer Windy, thank you so much for giving us a peek into your life, into the things that you've dealt with and gone through, but also continue to develop in your own life. I appreciate you sharing with us this aspect of your journey.

Thank you.

That's it for this episode of Living Blind. Thank you for tuning in and getting to know Windy Ho Li. Special thanks to executive director, Debra Gold and the entire team at BALANCE for Blind Adults. If you liked what you heard today, subscribe and follow us on whatever platform that you're listening on right now.

And we're also on Facebook, Instagram, and Twitter @BalanceForBlindAdults. For more information about BALANCE for Blind Adults and our programs and services visit balancefba.org. I'm Ramaya Amuthan the host of today's episode, and this has been Living Blind.