

Michael Ward

[00:00:00] **Brittany:** [00:00:00] Welcome to Living Transplant.

[00:00:01] **Courtney:** [00:00:01] The podcast that takes you behind the scenes of the transplant program at Toronto General Hospital,

[00:00:06] **Brittany:** [00:00:06] and brings you open and honest conversations about the transplant experience.

[00:00:10] **Courtney:** [00:00:10] My name is Courtney and I'm the communication specialist for the Centre for Living Organ Donation.

[00:00:15] **Brittany:** [00:00:15] And my name is Brittany. I'm a bedside nurse in the Ajmera transplant center.

[00:00:19] **Courtney:** [00:00:19] Full disclosure: we are not physicians.

[00:00:21] **Brittany:** [00:00:21] No. And we are not here to give you medical advice.

[00:00:24] **Courtney:** [00:00:24] Think of us like your guides through the world of transplant, as we know it,

[00:00:28] **Brittany:** [00:00:28] Whether transplant is your past present or future your passion or your curiosity,

[00:00:33] **Courtney:** [00:00:33] Living Transplant will show you the world of transplant like you've never seen it before.

[00:00:38] Thanks for joining us for another episode of Living Transplant. Today's episode is all about exchanges between donors, donor families, and transplant recipients. Our guest today is Michael Ward, Provincial Family Services Advisor at Trillium Gift of Life Network. Thanks for joining us today, Michael.

[00:00:52] **Michael:** [00:00:52] Thanks for having me.

[00:00:53] **Britt:** [00:00:53] Yeah. So Michael, what is Trillium Gift of Life?

[00:01:00] [00:01:00] **Michael:** [00:01:00] So the Trillium Gift of Life Network is the agency of the Ministry of Health, which is now Ontario Health, as we all know it, or close to it. And we are the organization responsible for organ and tissue donation and transplantation in the province of Ontario.

[00:01:16] **Courtney:** [00:01:16] And what is your role at TGLN?

[00:01:19] **Michael:** [00:01:19] So I am a - what they call the family services advisor, responsible for making sure that donor families post donation are looked after, for lack of a better word.

[00:01:30] I think it's mostly so that they realize that once the donation process is over, that we haven't forgotten about them. Their decision to donate, their decision to support their loved one, doesn't go unnoticed or unattended to beyond that day. So that, that takes on different responsibilities. For my department where we focus on aftercare, which can be anything from a phone call to, reaching out by letters, which we do, for example, [00:02:00] early on, within about three or four weeks of donation.

[00:02:02] And, we'll call it an official letter, comes from me and it talks about the outcome. So it's, even though the family would already have an idea as to what the outcome is and how many recipients and where certain organs went, that letter comes as an official piece, but it also gives me the opportunity in that letter to introduce donor family services, that in the future, you're going to probably hear from me from time to time.

[00:02:26] And it gives them an opt out. So in other words, if they don't want that, past that outcome letter, they have an opportunity to, kind of say, it's like unsubscribe. And I think in the whole time I've ever been in this role, it's only happened once. So I think that, yeah, families, they, they want to know that, because then that explanation is like, if a recipient reaches out, do you want, do you want to know about, do you want to make contact back those, those kinds of pieces.

[00:02:52] And we touched base at one month, three months, six months, 12 months. Just by way of letter, just to say, we're thinking about you [00:03:00] and if there's anything you need. Right.

[00:03:02] **Britt:** [00:03:02] Do you think that people opting out or unsubscribing from that is like a way of grieving, although it's only happened once, but like, would you expect it to be some form of grieving process?

[00:03:13] **Michael:** [00:03:13] I think initially maybe people have that thought and then as they think about, as it's explained in that letter, it's like, Oh. They may have those moments, yes. In grief where that intensity is. So it's so new that it's like, I don't want anything to do with it it's over, but, I think the positivity of, you know, the donation piece, is what'll what keeps them attached.

[00:03:33] Right.

[00:03:34] **Courtney:** [00:03:34] And where does letter writing come into your meetings with them? Like, do you, is that something you offer to contact the recipient family or is it just something you kind of tell them about and wait for them to ask if they can write a letter?

[00:03:46] **Michael:** [00:03:46] Yeah, some, some donor families will ask right away. But in the six-month letter, it talks about writing to recipients and we give them that information in that letter. And the reason why we wait six months is mostly because, the feedback [00:04:00] from transplant programs, at least at the six-month mark, recipients know where they're at, and so within that six months they're adjusting as well. And it just doesn't put the, the pressure on them. But, some donor families will reach out. Some donor families will have already heard from a recipient at that point, and so there's no timeframe that it can happen earlier. It can happen, later. Right.

[00:04:22] **Courtney:** [00:04:22] So roughly how many letters would you say go through TGLN each year?

[00:04:26] **Michael:** [00:04:26] So I always give the number of a thousand pieces because there's 500 coming in. In other words, the letters that are coming in, either from recipients or donor families, and then there's obviously 500 going back out again.

[00:04:38] **Britt:** [00:04:38] Right.

[00:04:38] **Michael:** [00:04:38] So the handling is, is about, is about a thousand. It's amazing. Actually,

[00:04:44] **Britt:** [00:04:44] Do people ever write and not get a response?

[00:04:47] **Michael:** [00:04:47] Yeah, often. It's - but that, that can be based on all on a lot of things too. I think for donor families, as, as an example, most of them can't wait to know.

[00:04:56] Right. Which, which makes sense. But they also know [00:05:00] that recipients again are, also recovering from the transplant. Yeah. Certainly instances where I can tell by the date of the letter. And I look at the date of the transplant that a recipient, you would think that they're writing it in their bed before they're discharged from the hospital. It's - they just want to shout it from the mountaintop, kind of situation. And then others will wait to their first year of their transplant, like their anniversary. And I think often, as I try to explain to donor families, if they think, or, or ask why they haven't heard from them, it's because, the post-transplant coordinators, who know their patients better than anyone else, give great information. They will, they will say to a recipient we don't want to tell you not to reach out, but we understand too, that your donor family is going through their year first without their loved one. In other words, that birthday has to happen, that anniversary or holiday. And so, you being mindful of that can be helpful sometimes. But that's not to say that if you want to write that you can't, because I have donor families that just [00:06:00] can't wait to hear. Right. So it runs the gamut of, just depending on the situation, how the donation came to take place, whether it was a sudden death. Yeah. In that, in that it was a tragedy, and so, yeah, we're all different that way. I think each of us would, would probably have a different answer for what we think would be a realistic timeframe around a letter going out or, or a letter coming in.

[00:06:24] **Courtney:** [00:06:24] Right. For sure. So walk us through the process as if we are, I guess, who would be, if we were working with you, we would be a donor family, right? Correct.

[00:06:35] **Michael:** [00:06:35] Well, generally it's recipients that reach out first.

[00:06:38] **Britt:** [00:06:38] Or I'm a recipient. What do I do?

[00:06:40] **Courtney:** [00:06:40] There we go.

[00:06:40] **Michael:** [00:06:40] Okay. We'll pose it that way. So recipients are aware of the process, based on information that would be with their post-transplant coordinator. So if they said, I want to reach out to my donor family, there would be a similar process as from

my end to their end. So there's a, knowledge of what [00:07:00] they can and can, or should and shouldn't write to disclose their identity right now, some kind of forget cause they get carried away, but we redact and then edit that out. So they bring that letter into the transplant coordinator or post-transplant coordinator. They then send it directly to me. And then, because I have the knowledge of where the donor families are, I then make sure that letter is suitable to go out and then I send it directly to the donor family.

[00:07:24] **Britt:** [00:07:24] Michael, is there only one of you?

[00:07:26] **Michael:** [00:07:26] Correct. No, I'm kidding. I'd like to say that.

[00:07:29] **Britt:** [00:07:29] I was like, wow. Like the amount of letters that you're getting.

[00:07:32] **Michael:** [00:07:32] Yeah. We have, we have there there's two of us, and so we, we split that process cause there's other, other things going on, obviously that are just not correspondence letters. So we, keep busy that way, for sure.

[00:07:45] **Courtney:** [00:07:45] So how has COVID affected the whole process of letter exchanges?

[00:07:49] **Michael:** [00:07:49] I would say that it really hasn't. But in the beginning as everyone else, was trying to absorb what was going on around us, personally and professionally. I think there was probably maybe a couple of weeks [00:08:00] where, we noticed that, the volume, was a little bit down, but then it kind of went right back up again. And I think people then realized, maybe this is the opportunity to reach out, both ways. And so, we also in, in mid-April sent a letter through our, newsletter, to our donor families that we do three times a year. Just a little note that, that talked about, the vulnerability of, the recipient and how they might be feeling. And so, I'll share a paragraph or two of that letter that, that went out:

[00:08:29] Now more than ever, we know how crucial it is to stay connected with others. We've been receiving correspondence between recipients and donor families. During these days of isolation playing a role in the exchange of words of gratefulness and encouragement is a wonderful part of our family services program. It reminds us all that the initial altruistic act of human kindness does not end at donation. Transplant patients are particularly vulnerable and isolated during this pandemic due to their unique health challenges. We know that hearing from you, their donor family would lift their spirits. [00:09:00] A few words to say you were thinking of them and wishing them good health would be an enormous boost right now. And perhaps knowing you have given comfort to them may give you a boost as well.

[00:09:10] And then we just remind them where the guidelines to writing that letter is. So the response to that we could tell there was a bit of a spike, for those that, that, that follow the newsletter and, yeah, it, it just kind of carried on. So that's a wonderful, wonderful thing that covert hasn't, hasn't diminished the, the want need and desire of those two sides.

[00:09:33] **Courtney:** [00:09:33] Well, I guess it wouldn't really anyway. Because these people aren't meeting up in person, so it's always been this kind of distanced form of communication. Yeah.

[00:09:41] **Michael:** [00:09:41] That's exactly right.

[00:09:42] **Courtney:** [00:09:42] For sure. Yeah. Are there any letters you can share with us that have been written during COVID?

[00:09:47] **Michael:** [00:09:47] Yeah, for sure. So this, this particular one was interesting. The timing had nothing to do with the letter that we sent out. This, this actually kind of spurred on, the idea to send that, that note out in the newsletter, [00:10:00] this one's a little longer but this, came from a donor family to a recipient. I shared this also network-wide like in our organization because I just thought, nobody's in the office. Every once in a while, I'll, I'll send an internal letter just to just kinda let everybody know this, this is the work we do as an organization. And it's just a good reminder of no matter what department you live in, here's the baseline, right? So this comes from a donor family:

[00:10:26] To our dear recipient,

[00:10:27] We are so happy that you are doing so well in your last note to us, it is so very helpful to our family when you write. These past three years have moved both quickly and painfully slow. There are the times that make us pause and reflect deeply. This week has been one of those weeks, not for the loss of our daughter, but for the real time, day to day events as they unravel and make us all pause in disbelief. We want you to know that as we all navigate this unknown future, you are very much in our thoughts and hearts. We know for recipients that [00:11:00] this is always a priority to protect your health. Please know that we have our arms of love and support around you. We don't know you, but knowing of you makes us think of how we would support all family members through this time. You're most definitely an extension of ours.

[00:11:16] We can't take away your fear or anxiety around staying healthy, but we can most definitely promise you that we are following all of the recommendations that will help stop the spread of this virus. We hope that it helps you knowing that your donor's family is on this journey with you.

[00:11:32] Your donor would have been leading the charge for our family if she were here right now. Always the organizer and the one to remind us of how we can shift between having to be right or be responsible. We can assure you that in our small corner, we are being responsible and doing our part for you all recipients, our family and our community.

[00:11:54] With so much love, health, and courage,

[00:11:56] Your donors' family.

[00:11:59] **Britt:** [00:11:59] Perfect. [00:12:00]

[00:12:00] **Michael:** [00:12:00] Pretty succinct. Yeah. It doesn't get much better than that. Yeah. And to think that they, just knew to reach out. Yeah. And I have no doubt that there's other donor families have thought the same

[00:12:11] **Britt:** [00:12:11] Have letter exchanges always had the same type of role or process, like even, maybe not during a pandemic, but hearing about different viruses or illnesses or during the flu or any type of situation in the past, has it always been like that where a donor family may reach out to their recipient and be like, Hey, I know it might be a really scary time or is this kind of something that we've just noticed through COVID.

[00:12:39] **Michael:** [00:12:39] Yeah, I would say, just notice through your COVID, because we've never really had anything that stopped all of us in our tracks.

[00:12:46] **Courtney:** [00:12:46] Right. And that affects us all.

[00:12:48] **Britt:** [00:12:48] Made everybody, like, literally look back in their life and be like, hold on just a second.

[00:12:53] **Michael:** [00:12:53] Lots of reflection for sure.

[00:12:54] **Britt:** [00:12:54] Absolutely. So what's been the biggest change since you started your role at TG - [00:13:00] TGLN.

[00:13:01] **Courtney:** [00:13:01] Nailed it. Yeah.

[00:13:02] **Michael:** [00:13:04] You guys of all people should know that in healthcare we live in the world of acronym, right? TGLN is not so much a mouthful. Pretty much volume. It's I, and I think where that stems from is, more donors equal, more transplants equals. Yeah, more recipients. Right?

[00:13:21] **Courtney:** [00:13:21] Right.

[00:13:21] **Michael:** [00:13:21] And as long as a donation increases, which is the goal, right, that's why we do what we do. That will be a natural progression, for, for those to increase. And I think too, there's also, a culture of understanding whether it's, just better education, that people, they know to do it right. Even in some of our communication to donor families and through, the education to recipients from their post-transplant coordinators, it's the right thing to do; that, that acknowledgement piece. It doesn't mean that it's going to be easy or that everybody's going to do it. But certainly, the awareness that, that, that, that back and forth can take place, it keeps [00:14:00] growing.

[00:14:00] **Courtney:** [00:14:00] So. I don't know if you said this already, but I'm just wondering when and how the letter exchange program started. And if it was a struggle to try and allocate resources and support for letter exchanges, and how did people kind of defend the need for, for a donor families and recipients to be in touch with each other?

[00:14:19] **Michael:** [00:14:19] So Trillium has been around since the early two thousands. And when I came, it was a well-oiled machine as far as correspondence and letters. Before us, there were two other organizations that were doing a little bit of that, but, but not on

the same scale. And I think that was based on resource. So when, when Trillium came into being, they made sure that family services department was there, and made sure that, that process was, was a priority.

[00:14:44] **Britt:** [00:14:44] Michael, do you see any changes coming in the process of how letter exchanges happen in Ontario?

[00:14:51] **Michael:** [00:14:51] I knew you were going to ask that question. So probably yes I did, because it's probably the most asked question by donor families. But [00:15:00] it's mostly about, changes in being able to meet. Right. And so, or how much information that they can share in those letters. Changes to the act that allow for a, when I say the act, the privacy act, they were allow for donor recipients, to meet, in Ontario, it's embedded in legislation. So that's different than other provinces where, the organization creates the rules or the policy around information that can be exchanged. And so, British Columbia, Alberta, Nova Scotia are now saying we're going to allow for that. Now there will be criteria that will surround the ability as to how that that goes.

[00:15:41] And I'll, I'll share that because people are always so interested. And if, and when the day ever comes, that, that opportunity can happen in Ontario, that criteria may look like, they have to at least, exchange three letters within a year. Because that also gives someone in my position who can [00:16:00] share it with someone, someone else within the organization that this seemingly looks like a healthy relationship. And then, beyond that, there, there would be, the sign off, on both sides that this is really, what, what they would like. Just not quite sure what that is going to look like when the day happens. And I know that my colleagues across the country, who I talk to weekly on all, all different reasons, because organs do leave the province. And so we have that connection piece to two different provinces. They're, they're treading very carefully and slowly, but it's it's happening. And so. I foresee other provinces following suit and it makes it difficult because what, now we're seeing stories in the media about people meeting and not just people who met maybe by chance. And so, people say, well, how can that happen? Where, why are we not able to do that? And so you go through the explanation one more time, around why that can't be here. [00:17:00] And it is disappointing because I think there are certain situations that it would just be lovely if they could, they could connect. I mean, that's, my thoughts on it, but, I also know that there is reasons to protect that,

[00:17:10] **Courtney:** [00:17:10] Yeah, can you explain some of those reasons?

[00:17:12] **Britt:** [00:17:12] Would volume be one of them? Cause there are so many transplants.

[00:17:16] **Michael:** [00:17:16] Resources would be it, there would have to be a designated a program to support that, if we were going to support that. So, whether it included social work counselors, because, it's one thing for a program to say that they're going to begin this, but they, they I'm sure need and know that they need to have the infrastructure to support it. And if something went awry, which things can whether, just relationships like, like anything else, who then is responsible for that, going, going, ah, south? And so we can say, or any organizations could say, well, you signed off that, you're on your own now. We're not

responsible for what happens. But that's still really difficult. Because at the end of the day, we, we, facilitated the [00:18:00] beginning of it. So it, it really needs to, be taken slowly here just by the sheer number of, of, donors and recipients that we have in Ontario. Right.

[00:18:09] **Courtney:** [00:18:09] I guess, well, we've talked a little bit about the problems with meeting one another in person, I guess there would also be risk to, to meeting in person as well, but putting that aside? Are there risks to an exchanging letters?

[00:18:23] **Michael:** [00:18:23] I wouldn't use the word risk so much. But it is, it is a good word because I think, when any of us put ourselves out there, in that emotional vulnerability piece and I'm, and I'm thinking about donor families, more so when I answer this, that there there's a risk to writing and not hearing back for example.

[00:18:42] **Courtney:** [00:18:42] Right.

[00:18:42] **Michael:** [00:18:42] Or, or, there, there's a romantic notion of what all recipients must be like, right? Right. And so they can receive letters back and forth that it's, I wouldn't say disappointing, but they might, they might think, Oh, [00:19:00] I didn't, that's not who, who I thought the recipient might be. Right. Based on what, the information that they've shared. And this is interesting, cause it goes back to a conversation that I have with post-transplant coordinators all the time. They'll sometimes give me the heads up if they say, Hey, I'm sending you a couple of letters today. You might just want to take a look at that one. I asked them to just, scale some information back around, their thoughts on religion, for example, which is always one that we need to be careful about. I obviously talked to donor families a lot, but when they're writing to recipients, you never know who you're writing to and so that's, that's just something to keep in mind. But it's also, for some donor families, a two-edged sword, because it reminds them obviously, of the loss of their loved one, but almost all that I talk to say that pendulum swings very, very quickly to the joy of receiving a letter from a recipient.

[00:19:48] **Britt:** [00:19:48] Hmm.

[00:19:49] **Michael:** [00:19:49] And so it goes, that goes back to, the timing when I was talking about the year of firsts, they're saying, why are we not hearing from any of the recipients? And I'll say, well, they're, they're being mindful of you, but they also want to [00:20:00] be, well. They want to be able to write to you, thank you, and say my life has changed and not all recipients is, in my understanding, have the ability to make those statements within a couple of months. Right, right. Yeah. And so in fairness to them, and again, and through the education, thank goodness of, many post-transplant coordinators that I talked to, they do ask me, your message back to your donor family needs or donor families needs to be this, because they will protect their patients, the recipients, at all costs. And so, that is, it's just an important message that donor families understand about the recipients too.

[00:20:34] **Britt:** [00:20:34] Yeah. Hmm. In one of our interviews we had asked, one of our he's a recipient about writing letters and he explained the grieving process of having to

accept the fact that someone had to die in order for him to live and being able to write that letter was - or even just like wrap your head, wrap his head around -

[00:20:58] **Michael:** [00:20:58] It's daunting.

[00:20:58] **Britt:** [00:20:58] Yeah, of course. [00:21:00] It's just like,

[00:21:01] **Courtney:** [00:21:01] How do you get over the guilt?

[00:21:03] **Britt:** [00:21:03] Right? Like he called it survivor's guilt. Yeah. Yeah, sure. He was, he was talking about that. Survivor's guilt. And just being able to come around to the idea of writing to his donor.

[00:21:16] **Michael:** [00:21:16] Yeah. That's one of the conversations, that's one of the conversations I have with donor families too, is that, as well as telling them, about the recipient, being respectful of knowing they're going through their year first and the loss of their loved one, that there is a guilt, they know what had to happen in order for them to live right. And most donor families, in fact, I would say the majority would go, we get it. But I also say as time goes by, because there are many recipients who just don't know where to start. It has nothing to do with not being grateful, not wanting to reach out, but they just don't know how to just put that pen to paper and start. And so I will say to a donor family, if you reach out because we have, we have a, do the [00:22:00] guidelines on our website as to how to, to write to your recipients sometimes, that's giving them permission, right? Because you write to the recipient and it's Oh, there, they may be ready to hear from me. I didn't know what to say. They've given me a little bit of information as the, how hope, hope I'm doing well. And it's interesting because nine times out of 10, when donor families send letters and they usually send multiples. If there's multiple recipients, they may send the same letter, generic, and then I'll send it to the different recipients, there's always a response. And so that just feeds into that theory for me, that the recipient was just waiting to hear first. So they could, they could make contact knowing that their donor family was ready to hear from them.

[00:22:43] **Courtney:** [00:22:43] That's interesting. Because I feel like in living donation, it's the other way around where they want the recipient to reach out to them. Well, I guess it, in living donation, when it's anonymous donation or non-directed donation, they can only exchange one letter each. And [00:23:00] then I feel like a lot of donors that I've spoken to, they don't want to, they want the recipient to reach out to them first because they don't want to make the recipient feel pressure that they have to be grateful where or anything like that.

[00:23:11] **Britt:** [00:23:11] When the donor does have multiple letters that they give out and the recipient is writing back, does the recipient in that sense mention, or are they allowed to mention which organ they got?

[00:23:26] **Michael:** [00:23:26] Oh, absolutely.

[00:23:26] **Britt:** [00:23:26] Okay. Okay. Okay. So they would say I got my kidney from whatever. Right.

[00:23:31] **Michael:** [00:23:31] Okay. That's key to keeping me organized. Right.

[00:23:35] **Britt:** [00:23:35] Because then you can be like, which one was this?

[00:23:38] **Michael:** [00:23:38] Yeah. Yeah. And the cover letter that would, that, that would go along with the piece of correspondence that the recipient has written to the donor and he says, I will say in that cover letter, here's this, a letter from your, your son's heart recipient and your daughter's getting your into yours. Those kinds of pieces is there that way when they're writing back, they'll say dear kidney recipient, right. And they can keep in line who they've heard from, and, those kinds of things. [00:24:00]

[00:24:00] **Britt:** [00:24:00] Do you find that depending on which organ they got the donor families, it's harder for them to receive based on which organ.

[00:24:08] **Michael:** [00:24:08] I dunno, I dunno about harder, but certainly, when there is a heart recipient, I think we all know, in our culture and, heart, the heart is just representative of, of, so much. And so, that is most definitely, the recipient that when there is a heart recipient, the donor families inquire about, or really want to get to know, or, or hear from, they are happy and, to receive letters from all recipients. But, but if I was asking, answering that question, accurately, it would be, that is, that is the organ that really stands out.

[00:24:40] **Britt:** [00:24:40] I get that. After reading some of the letters, does it ever frustrate you hearing one side or another side or being the middleman? Does it ever frustrate you knowing both sides of the story?

[00:24:54] **Michael:** [00:24:54] Frustrating, but it, it speaks to, maybe that thought, if our privacy act was a little bit different, [00:25:00], where these, these people could come together again, like, just be loved.

[00:25:04] Yeah, this would work. Yeah. I'm quickly reminded that there could be a situation that maybe couldn't work. Yeah. Or, and maybe, maybe shouldn't.

[00:25:15] **Courtney:** [00:25:15] Yeah, well, yeah, I feel like we see it a lot now. Well, transplant in general seems to be changing and living organ donation as well with how people find one another on social media. So either finding your living donor through social media, or, I feel like there's a bunch of Facebook groups now where people are, trying to, find their, their donor family and their recipients. Like people will post the date of death or the date of their transplant kind of looking for their match. What are your thoughts on people who kind of like circumvent the system to meet this way?

[00:25:45] **Michael:** [00:25:45] Yeah, it happens, often. Yeah.

[00:25:47] **Britt:** [00:25:47] Do they tell you, do they tell you? Say like I met my donor family and you're like,

[00:25:51] **Michael:** [00:25:51] Yeah. I would get it opposite. I would get the donor family would say I've met the recipient. But I, I have [00:26:00] often received the heads up from a post-transplant coordinator and say, just want to let you know that they found their donor

family. And so at the same time, neither the transplant program nor TGLN would ever confirm or deny that. Right. Because that would just, right. Yeah.

[00:26:16] **Courtney:** [00:26:16] And you guys would never intervene either.

[00:26:19] **Michael:** [00:26:19] Nope.

[00:26:19] **Britt:** [00:26:19] It's kind of like a hands-off situation. Like you did this on your own. You're not getting involved.

[00:26:25] **Michael:** [00:26:25] We certainly don't encourage or discourage it, but there are, easy markers that will, show both sides, whether that, in fact, is their recipient or the donor's family, because if they've written back and forth a couple of times, and as Courtney has said on social media, where there are Facebook groups and all that kind of stuff, they just have to post their letter. And then there's your confirmation. There's your confirmation, which is we know transplant programs and TGLN we, we both know that that's generally how it goes.

[00:26:55] **Britt:** [00:26:55] When reading some of these letters, do they ever affect you personally?

[00:26:59] [00:27:00] **Michael:** [00:27:00] I wouldn't say personally, but they, yeah, they stop you in your tracks someday. And I think mostly, for me, it's, it's always paed. Right. And it's often we don't talk about, we think of donors as being adults mostly. Right. but in a perfect world, that would be the case maybe. But we have a lot of pediatric donors. And so, that, though the letters between, the parents of the recipient to the parents of the donor are just, yeah. Yeah. You need to like get up from your desk and go take a walk generally after reading them because the emotional exchanges is, there's nothing like it.

[00:27:38] **Britt:** [00:27:38] Do you have any letters with you?

[00:27:40] **Michael:** [00:27:40] I did bring a couple. One, interestingly enough, which I've, shared often and with permission I might add, was from a, a young girl, like very young girl, who is in a grade three and in handwritten as a little one in [00:28:00] grade three would be writing. It's certainly legible. But you can tell that it's in a child's handwriting. So those are always like, Oh man. Yeah, exactly. Tissues. Yeah, exactly. Yeah. She, is a heart recipient. And, she's talking about how everything is going for her, but it's, it's her one question that kind of really threw me, because it's, it's just so cute. So I'll read this letter:

[00:28:23] To my donor family,

[00:28:25] I'm in grade three. I'm always smiling. Checkups are great. I love my cat and dog. I like Legos and Barbies. I have a question about my donor. Did my heart come from a boy or a girl?

[00:28:39] And so in talking with, the transplant coordinator about this, she'd never played with Lego much, and not that girls can't play with Lego, but she was just like, she thinks though that must be a boy thing, which we all know it's not, but it was just so cute for her to write. I like both. So -

[00:28:57] **Courtney:** [00:28:57] what does this mean?

[00:28:58] **Michael:** [00:28:58] Yeah, a male or [00:29:00] female. So. Then she closes: thank you so much. The greatest hero I never knew was the organ donor who saved my life.

[00:29:08] **Britt:** [00:29:08] Yeah. Sorry. That's really cute.

[00:29:15] **Michael:** [00:29:15] Yeah.

[00:29:15] **Courtney:** [00:29:15] So cute. Oh Britt.

[00:29:22] **Michael:** [00:29:22] Yeah. Welcome to my world. The best job in the world, I will, I will add. This next letter, I'll write a, or I'll read a paragraph. This is from a recipient's mom, to, to the donor family and just, one of the paragraphs, which is what just is, is a great, reflection of, of how content can be in a letter. Imagine how wonderful this would be to - be received by, a donor family from, from a recipient, a mother.

[00:29:55] Today, our daughter is thriving and is our greatest joy. She enjoys watching [00:30:00] cartoons, playing with toys, going for stroller rides, swinging on swings at the park and listening to music. She likes to babble and make noise and seems to have her own special language. She has her own unique personality is very strong willed and can be a wee bit stubborn at times. Exclamation Mark. We are blessed to have family and close proximity and they love spending time with our daughter. We understand that with our joy, unfortunately comes sorrow for your family. We can never truly understand how you must've felt on that day. We can never even hope to thank you enough for the decision that you made to save our daughter's life saying thank you just as not seem enough, considering the amazing gift that you provided to our family.

[00:30:42] And that's coming from a recipient of, a little one that was just months old. And so just the, just the gratefulness, the humanistic piece. And I just, in this particular situation, I, I, had been talking with, the parents of this donor, quite a bit. So they, they [00:31:00] were in a place where they just couldn't wait to get this letter. And in most situations in paed, I will give, or make a phone call to the, the donor's parents saying this letter is arrived, it's coming, where are you at? Do you want to, are you ready to, to see it? And in most cases it's like, yes, send it on. But I think it's just the responsible thing to do to, to make sure that they, they have an opportunity to take a breath before they go to them.

[00:31:26] **Britt:** [00:31:26] I never even thought of that. So, this might be a dumb question, but do you email them or do you actually mail them or do you get them in an email or do you get them by letter? Cause it's 2020.

[00:31:39] **Michael:** [00:31:39] Yeah, right. No, no, no, no. For sure that, that's a, that's a great question because, now a lot of people do email the letter. Why that hard copy letter is nice is because sometimes they're, a lot of them are handwritten, a lot of cards with a note. But sometimes people who are just so prone to be on their computer, it's just like, they [00:32:00] can write it. They can get those feelings out, those words out in a, easier format and it's right there and they can just press send. Right. Otherwise they just might not be as

motivated or., have the ability to, yeah, I'm going to get to that, but when you're right in front of your computer and you can send it to me and

[00:32:16] **Britt:** [00:32:16] So you said that when it comes to like the pediatric letters, you maybe confront them and say, hey guys, are you ready for this?

[00:32:24] **Michael:** [00:32:24] That's just my approach. That's actually just a personal approach that I've just said at the very least, And, and I actually, heard it. They said, it was lovely to get this letter, and this was early on when I started, we could have just like, we would have like the heads up, my wife was alone, she opened the mail. I was at work. And it's like, I get it. I apologize. And they weren't really, like, they were not upset. He was just saying like, FYI, that would have been better. We love the letter. I just would have been nice to have it. And read it together, not knowing that she just opened it because it's like, Oh, what's this? Yeah. It was a learning that was a learning curve for sure.

[00:32:59] **Britt:** [00:32:59] Yeah. [00:33:00] Yeah. That's fair.

[00:33:02] **Courtney:** [00:33:02] So I can only imagine that writing the letter, whichever side you're writing from is, is pretty daunting. Do you have any advice for, for people that are hoping to write? And what are some of the, some of the tips or the advice that you would offer them?

[00:33:14] **Michael:** [00:33:14] Yes. So for recipients, if, and when I'm asked that the answer is pretty basic, and it's just like, if you, can't put a bunch of words together, then just the thank you. And, and we do receive cards, but that's all it says. It says, thank you. And donor family would rather hear that than nothing at all. Yeah and so the number one tip is to acknowledge the death of a loved one. If I'm going to give like a tip for right out of the gate, and then you can go on to talk about, how grateful you are for the gift, that they said yes, talk about how it's changed your life. I don't have a [00:34:00] lot of interaction with recipients, but for there, there are some that I do because, we have recipients that may have been transplanted in Ontario, but they're, they actually live in another province now. So they really don't have the same connection ability to their post-transplant for them. Because they're probably being seen by, a specialist in the province that they live in. So then we just kind of, we have that one way, one way street back to, to us. And what that does is it just speeds it up. So it's like, there's not a delay from where they used to be seen right.

[00:34:29] **Courtney:** [00:34:29] What are some of the longest letter exchanges that you know of?

[00:34:32] **Britt:** [00:34:32] And is there a limit to the amount of letters that someone's allowed to give?

[00:34:37] **Michael:** [00:34:37] So we have donor families and recipients that have been easily, especially in, in the, in the kidney programs that have been exchanging letters for 20 plus years. Thank goodness they do it regularly because some donor families move and then they don't, they might make a change of address everywhere, but they don't think about TGLN. And so if a recipient [00:35:00] who, let's just as finally has the, the, ability to reach out and thank their donor family, and for some realistically, it can take years to do that,

sometimes we can't forward their letter because we don't know where the donor family went. Our last known address was this, and then it comes back. Yeah, it is. It's, it's unfortunate. Because, that maybe that donor family would have really loved to hear and as well, disappointing as well for the recipient because, something could have been, could have been started as well. And I'm sure there, they may be wishing they had written earlier, but that's no fault of theirs because they just weren't in a place to do it.

[00:35:34] **Britt:** [00:35:34] Right. Yeah. So is there a limit there's not a limit then? No, per year.

[00:35:40] **Michael:** [00:35:40] No, no, not at all.

[00:35:41] **Britt:** [00:35:41] Just keep going, if you can, or want to.

[00:35:43] **Michael:** [00:35:43] Most that have that ongoing, it's, for sure, like the anniversary, around the, the transplant, some we'll call that some recipients we'll call that like their, their, their second birthday, those kinds of things. There's always, a major surge, in December at, just before [00:36:00] Christmas, like end of November. It's like, there's, there's generally a lot going back and forth and it's it's equal people reaching out, and they will sometimes use that date versus their, their transplant date, I think just to take away from, as it was explained to me once, the date of the death. So let's turn it into, let's turn it into like, a holiday, not assuming that everybody, celebrates Christmas. And especially in this day and age, which also leads me just to a quick point around, why some donor families don't hear, hear from recipients because sometimes there's language barriers that just don't allow them to do it. And not that I can ever confirm that that's the case or why they haven't, they haven't heard from, but in speaking with some post-transplant coordinators, they'll say, the likelihood of them writing their donor probably isn't going to happen because there's just not the support to be able to do it.

[00:36:50] **Courtney:** [00:36:50] And just going back to your question about like, limits of letter exchanges. So for living organ donation for non-directed donors and their recipients, they can only ever exchange one letter each. So we [00:37:00] have, do you want to, should we read ours? We have a copy of, the only letters that these people will ever, ever send back and forth with each other, which is pretty crazy.

[00:37:06] Yeah. Okay. So this is from the donor to the recipient family. So they donated to a, a child.

[00:37:15] Dear recipient and family,

[00:37:17] I hope this letter finds you and your family doing well. I don't know what is, what it has been like for you and your family to live with a failing liver. But I imagine it hasn't been much fun. It is my sincere hope that your recovery is going well and that you will soon be able to enjoy life to its fullest and we'll have the chance to spend many quality years to come growing and being with family and friends, I feel honored to have been able to offer a little piece of me in the hope that you will have a life of health and happiness. That is all the reward I need. It was absolutely my pleasure to do this. I am fortunate that my recovery couldn't have been better. And if I could do this again, I wouldn't hesitate for a moment. I'm

the type of person that is always looking for an opportunity to help people. [00:38:00] Sometimes it's just a little thing like paying for the order for the person behind me at Tim Horton's drive through or putting some coins in the cup of a homeless person. Sometimes it's something more. Whatever it is, I try to make the world a better place. Even if just one act of kindness at a time, that's what brought me here. I am so pleased to have the opportunity to help someone like yourself. And while I certainly hope it helps you. It also allows me to give back, perhaps someday you can pay it forward in your own small way, and we can all help make the world a better place.

[00:38:33] I wish you a speedy recovery and a long happy, healthy life.

[00:38:38] **Britt:** [00:38:38] Thank you. I feel like I'm the recipient and I'm going to read back my response. Okay.

[00:38:45] Dear donor family,

[00:38:47] It has taken us some time to write this letter because there are no words that could ever express our gratitude and appreciation. You've given us the best gift possible, the gift of life. And for this, we could never thank you enough. [00:39:00] Living with liver disease was hard and scary at times, but immediately after the surgery, we saw remarkable health changes. We now have a healthier and happier child. And this is because of you. Thank you so much. We received your letter and brought tears to our eyes. It is truly amazing that there are people like you that want to make this world a better place. And what better way to do this by saving the life of a child, your act of kindness and selflessness has inspired us to make a difference. We want you to know that our family's committed to making a difference and we will help make this world a better place. We are so glad your recovery went well. There's many times during and post-surgery surgery I wondered how you and your family we're doing. It is nice to know that you are doing well from the bottom of our hearts. Thank you and your family for being our donor. We will be forever grateful to you. And we love that a piece of such a kind and wonderful person will be in our little one forever. We wish you a life full of happiness and good health love, always your liver, [00:40:00] recipient and family. Thanks, Courtney.

[00:40:04] **Courtney:** [00:40:04] All they'll ever get to exchange with each other. It's so sweet, but it kind of makes you a bit sad, but that's all, that's all they get.

[00:40:10] **Britt:** [00:40:10] Yeah. But still enough to like bring you through.

[00:40:14] **Courtney:** [00:40:14] Absolutely. Yeah. Yeah. For sure. So you've been doing this obviously for a while. Are there any letters that you just can't forget? Yeah. That just like stick out that you're like, Oh my goodness. That one really?

[00:40:27] **Michael:** [00:40:27] Yeah. The one that I read for sure. It's, it's a favorite because, about question. Right because it's just so innocent and, and, then childlike. I think they, I, I don't have, I don't have a favorite because, I'm amazed every time one comes across my desk, whether it's from an adult or, or a pediatric, patient it's it's. what's next? And so what that does for me is there are some standouts as like the one I shared, but it just keeps adding to the story for me as [00:41:00] to just how people, in that altruistic moment rise

out of their situation, and say yes to donation. And so I'm getting a little bit, post that process where I get to learn a little bit about them because they're writing back and forth. Yeah. It just amazes me. So every letter for me in its simplistic form, or even some that are long and there have been some that are like seven, eight pages. Yeah, it's just. Yeah, I have the greatest job in the world.

[00:41:34] **Britt:** [00:41:34] Yeah. I won't speak for all nurses, but I will speak for myself that I don't feel like I get to see the humanistic part of it as often. Like we're very busy and we don't really get to talk to them as often as we, I think we'd need to in order to get that experience. So. I think what I've learned today is I can't work in paediatrics because [00:42:00] I wouldn't be able to do it, but amazing to hear those stories and just hear that other perspective outside of these walls, it's a lot.

[00:42:11] **Michael:** [00:42:11] Well, it's a reminder that, life is fragile and because, and not to focus on, on the pediatric piece, but it's just one of those reminders of the innocence of an expectation of those that, that have a family and children. And then it's like, what, what just went wrong? Whether it's the health of a potential recipient or, or losing a child, what's amazing is that organ and tissue donation can create something positive, and it, and it is because that's the word that's been used to me, out of a terrible loss. And that is what helps in the grieving process. And from my standpoint, in my department, that's, that's, our aim is to make sure that donor families don't feel like on that day, it's over and we get to try to help them along their walk with them [00:43:00] on that journey.

[00:43:01] **Britt:** [00:43:01] Amazing. you get a little piece of this too, right? Like letters?

[00:43:06] **Courtney:** [00:43:06] No, I don't have anything to do with letters. I interview a lot of living organ donors. So I get to hear like really, really happy stories. You know, there are some, some tragic ones in terms of what inspires people to become living donors. Right. but for the most part, I deal with just very very happy stories. Yeah.

[00:43:23] Well, thanks so much, Michael.

[00:43:25] **Michael:** [00:43:25] Thank you for having me. Yeah,

[00:43:26] **Britt:** [00:43:26] that was good.

[00:43:28] **Courtney:** [00:43:30] Thanks for listening to this episode of Living Transplant. If you have questions or suggestions for future episodes, email us at livingorgandonation@uhn.ca.

[00:43:40] **Britt:** [00:43:40] Don't forget to subscribe, rate, and review Living Transplant on iTunes, Spotify, or wherever you listen to podcasts

[00:43:46] **Courtney:** [00:43:46] and follow us @givelifeUHN on Facebook, Twitter, and Instagram.

[00:43:50] **Britt:** [00:43:50] See you next time.

[00:43:52]