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SPEAKERS

Nico Santos, Melissa McQueen, Christopher Byczko, Christopher Conover, Zac Ziegler, Darius Moezzi, Nicole Cox



Christopher Conover 00:04

Welcome to The Buzz I'm Christopher Conover this week organ and tissue donation in Arizona. Almost 1,400 organ transplants were performed in Arizona in 2023. That according to the Organ Procurement and Transplantation Network, but the state's waiting list remains that almost 1,700 people and 47 died while waiting for a transplant. Arizona falls right around the national average with 55% of people registered as organ donors. But what does organ transplantation in the state look like beyond the numbers? To start today's show, I spoke with Nico Santos of Donor Network of Arizona, the state's organ procurement organization. We started our conversation talking about what the organization's work consists of,



Nico Santos 01:03

That's starting off with a loaded question already. Yeah, the organ donation for transplantation system is pretty complex. And in fact, it's segmented. So Donor Network of Arizona is the organ procurement organization. And that's basically a fancy word for we handle the state's registry of people who register as a donor, either at the MVD or on our website. And then we are in contact and communication with the family members of donors, after this person has passed away to either walk them through the process if the person is already registered, or to communicate with that family, learn about the potential donor and determine if this person's values aligns with our mission, which is saving and healing lives.



Christopher Conover 01:52

So, for a lot of us, what we know about organ donation is what we've seen on TV what we've seen in the movies, we know that sometimes that's not perfect information. So what does Hollywood get wrong about organ donation?

N

Nico Santos 02:09

When we talk about organ donation, organ and tissue donation to be specific, we very consciously use the word or the phrase public education. Because awareness, pretty much everyone is aware that it exists. Now, the public education aspect is specific, because there are a lot of misconceptions. And we understand, you know, Hollywood, it's overdramatic, and they really toss accuracy out the window sometimes to make a compelling storyline. But a lot of the time, it's really wrong. And it's okay that it's wrong, except for the fact that when it's wrong, it actively prevents people from registering. Sometimes they remove their registry status because of what they've seen. And so it's preventing the gift of life.

C

Christopher Conover 02:56

Can you give me an example of the what's wrong with what we see on TV in the movies?

i

03:01

Yeah, I can't think of a specific show or example right now. But the oversimplified story that you have, like this medical professional, who maybe has this dilemma, because there's a patient and crisis in front of this person, but maybe they have fill-in-the-blank family member who's in need of a heart. The first thing I have a question about is, how would this doctor even know if the person who may become a donor through this is even a match? Really, the bottom line is, every medical professional title has its own version of what Hippocratic Oath. You have to do right by the patient in front of you. And frankly, it is the result of medical professionals in an emergency trying so hard to save this patient's life that even renders any of the organs viable for transplant in the first place. So if a doctor just hands off, we're gonna let you pass away because maybe you're an organ donor, it doesn't work that way. Then there will be no gifts to pass to the recipients who rely on our work.

C

Christopher Conover 04:03

They always, it seems like are in a rush. Is this a rushed process? Or because of the organ donation system? Do we get that rushing? It makes for good TV, but maybe not reality?

N

Nico Santos 04:20

There is some level of urgency when things happen on multiple fronts, even when we have large number of donors on any given year, and we're honored by such generosity from Arizonans. The waitlist is even longer. So yes, there is some sense of urgency, and particularly from the recovery of someone's gifts to the recipient, depending on what type it is. Maybe it's the heart for example. There are some exceptions, but historically, and typically, you have about four hours from donor to recipients. So there is a sense of urgency, yes. But there's a stage of this whole process, much of which lands kind of in our area of work, Donor Network of Arizona, which is donor care. So before the recovery of organs, this testing involved is a matching process, there's allocation. But also, even though this patient may be brain dead, for

example, there are other ways to donate. There's still donor care, and there's still a ventilator, there's still medications being administered, to make sure that these are the best gifts. And we find that for the best matching recipients.

C Christopher Conover 05:28

On a driver's license, if you're an organ donor, and you've signed up that way, there's the little red heart on it indicating that, but maybe you signed up after you got your license. You haven't renewed your license yet. How do you all know how does the hospital know that this person is willing to be an organ donor? Should that point arise?

N Nico Santos 05:49

Well, your question brings up two points,. When someone registers, we always ask them to share their registration decision with friends, family, loved ones, but not because we would require authorization from next of kin in such an event because they're already registered and it's a legally binding decision. But in the rare event that maybe the family didn't know, and this is a surprise to them. This is a pretty terrible time to be surprised. But the original question was like, how do we know? And that's a good question. Because there are multiple ways to register. The DMV, is the most common way. More than 95% of our new organ and tissue registrations happen through a DMV transaction. But you can also go to donatelifeaz.org to register. And it's all the same registry. Regardless of the way in which someone registers every hospital in the state is federally required to report all in hospital deaths to our organization.

C Christopher Conover 06:45

Since ours is an opt-in state, I believe there are some states where it's an opt-out state, you're automatically registered for organ donation. Does that change things radically? Or do enough people opt out that it's pretty much the same, do you think?

N Nico Santos 07:02

As far as I am aware, there are countries considered opt in, there are other countries that are opt out. But in the United States, every state has some form of the Uniform Anatomical Gift Act so it requires people to register in order to participate or even be considered depending on the circumstances. Spain, for example, is another high performing organ transplant system. Spain happens to be an opt-out system. And while on the surface, it sounds like, 'Well, everyone should just be an organ donor, kind of like by default. You'd expect someone in my position to say that, but Donor Network of Arizona stance is not in support of that for multiple reasons, including our country's founded on multiple and specific values, one of which is autonomy. So yes, we believe it's a great thing. And we are inspired by the generosity of Arizonans and others really. But it comes down to this person making the decision, or at the end of the day, the family can also make the decision on behalf of this person, should they not be registered in an opt out system? You know, let's assume that a given potential donor did register themselves opting out, I don't want to be assumed that I'm a donor than zero possibility for an entity like

ours would have zero possibilities of contacting family to secure authorization because the know was already registered. The possibilities in an opt in system like the United States are much higher.

C Christopher Conover 08:38

All right. Well, thanks for explaining all this to us.

N Nico Santos 08:41

That's what I'm here.

C Christopher Conover 08:43

That was Nico Santos of Donor Network of Arizona. Navigating the world of organ transplantation can be complex. That's where organizations like Transplant Families come in. The Arizona based nonprofit provide support and knowledge to families with children who are in need or who have had a transplant. Melissa McQueen is the founder of Transplant Families. I started our conversation by asking her about a recent opinion piece she wrote for the Arizona Daily Star.

M Melissa McQueen 09:17

We definitely have been kind of in a lull in the transplant system for quite a while. No new technologies have really come into play. We need to see innovation come into the field. It's a time where we've seen this happen in other areas. I kind of liken my area to pediatrics since that's what I cover with Transplant Families. But for diabetics, you've seen that they have insulin pumps, and they're able to keep track of their rates and everything through certain kinds of attachments to their arms and things like that. But what transplants, you aren't seeing any innovations like this. I know it's a smaller group, but I often ask any clinician that will listen to me, 'Hey, you know where's our pump for anti-rejection meds, immune suppressants?' We can certainly monitor that in the blood. Why can't we have new devices to help with that? It's so hard for young adults and teens, busy people on the go to keep track of these things all the time. Certainly, there's room for innovation, and for companies to make their mark in this area.

C Christopher Conover 10:21

So that post-transplant life that you're talking about is something very personal to you. Your son received a new heart as an infant. What's it like as a mom and for your son growing up, when recovering from that life altering procedure?

M Melissa McQueen 10:40

It was quite a shock to us when he was born with cardiomyopathy and shortly thereafter, he

needed a transplant. We went out of state to get care because we didn't have any place locally to go to. He was very sick very quickly, listed at six months. At eight months, we got the call. It was the same day they were supposed to put in a Berlin heart, but luckily, someone chose to donate and we will be forever grateful for that. He got his new heart, and he has been doing phenomenally ever since. He just had a really phenomenal recovery, and everything's gone well for him. Even then he was a baby who didn't get to do certain things and his development. So we had to come back and get early intervention processes. He didn't know how to eat, he couldn't crawl, he couldn't sit up. So we had to have therapies come in and help with all of that it took him many, many years to catch up. But he never shied away from a challenge. These kids there were amazing. He came back, learned how to eat, how to talk, how to walk, how to run, and this last week, he got third in the state for JV wrestling in his weight class. So that's the kind of grit that these kids have. They come ahead and they do so well, with proper care.

C Christopher Conover 11:58

Well, and you said he just got third in the state in JV wrestling. So not only did he learn to walk and talk and run and do all the things kids do, he's competing athletically also. So obviously, the transplant has really worked well for him.

M Melissa McQueen 12:15

He has done a great job. Now his next big challenge will be taking over his own care, you know. He's 15 now, but before we know it, he'll be 18. And in his 20s, and in college, and us as parents, we do so much for them. We'd like to see interventions available for them, where they don't have to take days and days off for care. That they can be a typical college students, maybe it's easier for them to get labs, maybe they don't have to go in for invasive heart catheterizations every year. It would be nice to have a blood test and just to carry on and live life as he was meant to live it.

C Christopher Conover 12:51

Your experience through all of this led you to found Transplant Families. Tell us a little bit about that journey, and also what the organization is.

M Melissa McQueen 13:00

Oh, certainly and thank you for asking. Transplant Families was kind of born out of necessity. My background is in software engineering, and with three kids under three, and my youngest being the recipient, I thought, 'I'm doing a lot of research to kind of try to find the best care for him. I might as well document it somewhere.' So I threw up a website which evolved. We connected with other people. A lot of people were coming to the site, they were liking it, and we connected with some support groups. And we were chaptering off when COVID happens. And when that happens, we were already kind of aligned with some quality improvement groups around the country, with clinicians in the heart, liver and kidney realm. We said, 'look, there's no guidance for this. We're all parents, we're used to kind of being in our own bubbles because our kids are immune suppressed. What can we do to give them appropriate guidance?'

We can't give it as parents, only the clinicians can do it. And so we kind of had a partnership at that time where we said, we're going to educate families in partnership with clinicians in the community. That's what we did. So it became a support, it became education. It became a collaborative community where we come together and share ideas, our successes, sometimes our heartaches, and hopefully those heartaches turn into solutions.

C Christopher Conover 14:15

It sounds like that community that you've helped foster, through Transplant Families and other organizations is really, really important. So that the the recipients and the families, they aren't going through this alone.

M Melissa McQueen 14:32

That's the most important thing. So many families before this, they felt alone because of the nature of being isolated. So they were on their own thinking they were going through this all by themselves. We've been able to provide this community, were able to talk to each other, ask questions and support one another through these huge milestones that these kids go through, or items when they're afraid, you know, like what if they get chickenpox, which happened to my son. I'm able to go ask, 'Oh, gosh, you know, we're supposed to be really afraid about this. Has anyone come through this alright?' And to hear those messages of support before you get to your next clinic visit is very, very important.

C Christopher Conover 15:16

Well, we will make sure for our listeners to put transplant families up on our website. So if anybody's listening to this and wants to find you and doesn't want to Google, it'll be right there. Thanks for spending some time with us.

M Melissa McQueen 15:31

Oh, thank you for having me. And thank you for spreading this word. It's such a wonderful group to be a part of. If we had to fall into any medically critical realm, transplant was certainly the best one. It's such a happy, thoughtful community. They're all so grateful for the second chance we've been given with our family.

C Christopher Conover 15:49

That was Melissa McQueen of transplant families. In the first half of our show, we heard about how organ donation in the state works and the lives that can save. Now we turn our attention to tissue donation. While more people receive donated tissue each year than received donated organs. The topic is discussed, notably less. Joining me now is The Buzz producer Zac Ziegler, who has spent a lot of time recently studying up on this industry. Zac, welcome.

Z Zac Ziegler 16:20
Good to be here. Chris.

C Christopher Conover 16:21
You edited those first two interviews of today's show. So you know what we heard about organ donation. How does tissue donation differ?

Z Zac Ziegler 16:31
Well, the biggest difference is time. We heard how sometimes when it comes to organ donation, there's only hours. Well, delicate tissues like cartilage or skin have days, maybe weeks. Others like ligaments and tendons, they can be frozen, which means they have a lot of time. That allows for one more link in the chain. And that link isn't just a middleman in this whole process. They really add some added value. JRF Ortho is one of the leading companies as far as orthopedic and sports tissues. And I say company but they are a nonprofit, and Christopher Byczko is JRF's marketing manager.

C Christopher Byczko 17:13
What happens first is similar to organ donation. When somebody passes away an OPO, or an organ procurement organization, recovers the body and then they move that on to the processing company, which is in our case we're owned by Allosource and Solvita, so either company can process the tissue.

Z Zac Ziegler 17:36
Now, he used that word 'processing.' That can mean a lot of different things from tests to see about donor match to preparation that removes blood or turns the tissue into something that wasn't before. So a donated Achilles tendon can be turned into a knee ligament. Processing of cartilage takes almost three weeks and the tissue is viable for about four. So there is still often that sense of urgency.

C Christopher Conover 18:01
Now you learned mainly about orthopedic tissue transplants, as you were just talking about. What are those exactly?

Z Zac Ziegler 18:09
So ligament reconstruction is probably about the biggest one. To learn more about this. I spoke with Dr. Darius Moezzi. He's an orthopedic sports surgeon practicing in Flagstaff. And he does the surgeries pretty routinely.

D

Darius Moezzi 18:23

I don't think there's been an increase per se, we've always used it for certain knee ligament reconstructions, cartilage restoration, typically and then the less so the shoulder, a little bit in the ankle. I was a little late for this interview because I just did a medial collateral ligament reconstruction in a young girl. So we used cadaver tissue for that, you know, an Achilles graft.

Z

Zac Ziegler 18:50

But my main introduction to this was the cartilage replacement. So particularly what's called an articular cartilage allograft, basically a cartilage transplant that includes a portion of bone.

C

Christopher Conover 19:03

Now this is where a little disclosure for our listeners kicks in. You started on this research, not necessarily for our benefit for reporting. You had one of these surgeries not too long ago.

Z

Zac Ziegler 19:16

Yeah, I became familiar with the allograft surgery because I had it November. To keep the disclosures coming, Dr. Moezzi did the surgery as well as another one on me in the past, and the tissue he used came from JRF Ortho. So leg issues have been a problem for me since I was a teen. I'm approaching double digits depending on what you call a surgery versus a procedure. And I had one on this knee about 15 years ago that's known as microfracture surgery that set me up for this surgery that I had to have. Dr. Moezzi described my issue as . . .

D

Darius Moezzi 19:54

A pothole, for lack of a better word, on your outer aspect of your femur, the lateral femoral condyle. And it wasn't just cartilage loss. But there was bone involvement too from your previous microfracture, and they didn't know any better. It's not like it was bad that they did that. It's just we know today that isn't going to work long term and it was wasn't filled with normal cartilage. And so you have this very classic appearing cartilage defect.

Z

Zac Ziegler 20:25

Now before November I couldn't run jump, my walking was limited to about a mile or so. In order to remedy the situation, I needed new cartilage and to have part of the bone issues removed.

C

Christopher Conover 20:39

When your doctor mentioned this procedure to you, what were your thoughts?

when your doctor mentioned this procedure to you. What were your thoughts?

Z Zac Ziegler 20:44

It sounded intense, and I had questions, which started me on this research path. But at that point, I was willing to try it because the other option for me was a knee replacement, which would have really limited me. Not to be mean, but I'm not that old when it comes to talking about replacing a joint. I just turned 42 before I had this. Doctor Moezzi said that's old for the surgery that I had, the cartilage allograft, which is usually done for people in their 20s and 30s. But what I was having was really I'm too young for a knee replacement.

D Darius Moezzi 21:19

If somebody is 60, yeah, you're probably not going to do a cartilage restorative or a joint preservation surgery. Sometimes it'd be nice, I mean, some 60 year olds may be healthy or more active than a 30 year old. You know, these things are expensive and it gets to kind of an insurance approval situation, and it's a little difficult to get these approved for you know, an older individual. And older that might be defined in our world as over 40, or at least defined by insurance.

C Christopher Conover 21:48

So what's more common this type of surgery, or a knee replacement?

Z Zac Ziegler 21:55

It's knee replacements by a mile. Christopher Byczko told me JRF Ortho is one of the largest companies in this field.

C Christopher Byczko 22:04

We've distributed over 25,000 since we've been around, and that was 2006. And that's just we're just talking cartilage, we're not even talking tendons and meniscus.

Z Zac Ziegler 22:14

And the American College of Rheumatology's website says there's almost 800,000 knee replacements each year. But my surgery is one of many sports orthopedic surgeries that use donated tissue. And there are also plenty of non sports or non orthopedic surgeries too. Donate Life says about two and a half million tissue transplants are done each year.

C Christopher Conover 22:39

Now we heard earlier that the list of recipients seeking organs largely outpaces the list of

now we heard earlier that the list of recipients seeking organs largely outpaces the list of available organs for transplant. Are things different when it comes to situations like yours that are tissue transplants?

Z Zac Ziegler 22:51

For frozen tissue samples, yes. Those are usually available quite quickly, verging on immediately. My surgery is one that can be tricky to get a donor for. I mean, knees wear out with age. And Byczko says finding that right match can be tricky.

C Christopher Byczko 23:11

So we can only supply what we have. The other variable here for you, is your surgeon is looking to get your knee matched with the correct donor tissue. And so depending on your size, you know, if you're a really big person, or really small person, you might be a bit harder than an average person

Z Zac Ziegler 23:32

For example, Dr. Moezzi said that in his experience, it's typical for what I had to take six to eight weeks to get the sample. I evidently was a special case, likely because of the size of the cartilage defect and my size in general. I'm about six feet tall. So it took almost six months to find a match.

C Christopher Conover 23:51

Now, because all of us in the newsroom, were aware you were waiting and things. We all have a very clear recollection. And it doesn't seem that different from organ donation regarding the notice. We were actually on our morning call, which for listeners is something we do every day, the whole newsroom gets together via Zoom. And you muted yourself and said, 'I've got to take this call,' and then came back on and said, 'I just got my donor. They've scheduled my surgery. That was a Thursday, they scheduled your surgery for Tuesday. And you basically said, 'I'll see you all in five weeks.'

Z Zac Ziegler 24:34

Yeah, and by the way, big thanks to Paola Rodriguez who did a wonderful job filling in for me putting these shows together while I was out. But yeah, like you said it was a pretty quick turnaround. The surgery, as you said, they called me on Thursday. It could have been as soon as Saturday, but we had to work around the hospital's schedule. surgeries with live tissue like this one, they have to be done in hospitals, not your typical outpatient orthopedic surgery center. So that was one more hurdle to have to go through. But yeah, things moved quick when they finally came through.



C

Christopher Conover 25:11

So your surgery was just before Thanksgiving. Obviously, those of us in the newsroom know how things are going, but fill the audience in on how the recoveries been.

Z

Zac Ziegler 25:21

It's surprisingly easy and life changing. I'm still months from being 100%. But you know, I've gotten to take my dogs for a walk a few times. I was out in the field for audio recording last weekend, which is something I haven't been able to do much lately. I'm currently up north for some follow up visits this week. So I've, you know, been having to do a little snow clearing and I'm thinking about maybe even trying snowshoeing this weekend, something the doctor told me I could do. Part of the reason I'm healing so quickly, my surgery went, like, really well. So in this clip, we'll hear Dr. Moezzi say, you can see this particular kind of tissue that really shows how well things went. It's called subchondral bone.

D

Darius Moezzi 26:10

And you can see that on X ray, it's kind of this white line, and the donor tissue will have that. In your case, it just lines up perfectly. Like I showed a couple of people in the office. So I was like, Look at this. It's just part because sometimes you kind of see where the donor is, and, and it was just a real just a perfect fit.

Z

Zac Ziegler 26:26

It's always good when your surgeon is pulling his colleagues over to show off how well your surgery went.

C

Christopher Conover 26:31

So true. So true. So what's it like to be on the other end of the transplant, even a relatively minor one, not that there's any minor surgery, but you had a relatively minor transplant? What's it been like to be on the receiving end?

Z

Zac Ziegler 26:48

You know, I've started to really realize how common it is to be someone like me, like I said, two and a half million people go through this a year in some way, shape or form. I chatted with Nico Santos, who we heard from earlier, when I was recovering from this surgery to get some background info. He was the first person to call me a transplant recipient, which really kind of changed my line of thinking. And I was talking to him also about my wife who had an anterior cruciate ligament replacement done some years ago that used a donor Achilles tendon. He also mentioned that yeah, she too is one, so my family really is. And when I use that phrase around friends, I started hearing more stories. I have a cousin that I'm very close to, his wife had a similar surgery to my wife. My dad is the only person I know who's had more orthopedic

surgeries than me. So I'm sure it's in there somewhere. I have another close friend of mine who has donated heart valves, and the list of donatable tissue is long. We haven't even mentioned much some of the other things they can use, bone, corneas, skin. Christopher Byczko really said it well.

C Christopher Byczko 28:02

When you get your license, driver's license, when you mark donor, that also means tissue and the tissue can improve a lot of people's lives. But also, you know, our parent companies, a lot of this tissue goes to spine and skin patients. And so there's a whole other world out there where you could positively affect people and one donor can affect over 200 people in a positive way.

Z Zac Ziegler 28:27

Now that I think of myself as a donor recipient, I'm definitely taking a step you hear a lot about when it comes to organ recipients. I'm getting my medical records from the hospital where the surgery was done. And JRF Ortho will help me pass along the letter to the family of the person from whom my new knee cartilage came. I can't wait to tell them what this will mean for me. I mean, I'm getting back to being active with my wife and my daughter. Plus, on top of that exercise is really my sanity and helps me destress. I'm so incredibly grateful. And I will also say this led me to doubly make sure that I too, am a registered organ and tissue donor.

C Christopher Conover 29:12

Zac, thanks for sharing your story. We're glad to have you back up and around and also sharing your research with us.

Z Zac Ziegler 29:19

Yeah, no problem. Glad glad to be here and to be back.

C Christopher Conover 29:23

And that's The Buzz for this week. You can find all our episodes online at azpm.org and subscribe to our show. wherever you get your podcasts, just search for The Buzz Arizona. We're also on the NPR app. Zac Ziegler is our producer with production help from Deseret Tucker. Our music is by Enter the Haggis. I'm Christopher Conover. Thanks for listening

N Nicole Cox 30:00

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