

Nicole Wells Discusses Liver Transplantation

Jennifer Cohen and Nicole Wells

Jennifer Cohen 0:04

Welcome back to voices in bioethics. I'm Jennifer Cohen and it's my great pleasure to welcome Nicole wells to the podcast. Nicole, thank you so much for joining us today.

Nicole Wells 0:14

Thank you so much for having me today.

Jennifer Cohen 0:17

Nicole Wells is a program manager for pediatric and rare liver diseases at the Global Liver Institute, a Washington DC based nonprofit organization. Prior to her position at the Global Liver Institute, Nicole taught English in the Virgin Islands. She's a native of Kentucky and graduated from Eastern Kentucky University with a bachelor's in English and education and a master's in rhetoric. Nicole, you are an expert on livers, specifically liver transplantation and that is because you are the recipient of a donor liver, the details of which we'll get into during our conversation. But first, I'm hoping you can help us out with getting some basics about the liver, and organ that, you know is vitally important, but I think one that most people don't tend to think about too much until something starts to go wrong because people can't feel it the way they can feel their heart or their lungs or other important organs. So, can you provide us with some basic education about the liver first? Where is the liver in the body?

Nicole Wells 1:18

Yeah, that is a great question. And I agree the liver is so misunderstood and underappreciated. And most people don't even know where the liver is. So it is right on your right side, if you put your right hand out and touch your stomach, as high as it'll go right under your breastbone, that is approximately where your liver is, and the liver is the largest internal organ in your body. So, it's kind of hard to miss it if you place your hand there.

Jennifer Cohen 1:51

Okay, how much does it weigh?

Nicole Wells 1.54

That is a great question as well. It is approximately around the size of a football and American football.

Jennifer Cohen 2.01

Wow. Okay, it's two lobed, correct?

Nicole Wells 2.05

Correct, yes. So, there's the left lobe and the right lobe and you can split it down the middle. And you can potentially have two full grown livers at that point.

Jennifer Cohen 2.15

Okay, and what color is a healthy liver supposed to be?

Nicole Wells 2.19

It is supposed to be a bright, pink or red.

Jennifer Cohen 2.24

Okay. That's incredibly helpful. Thank you for all of that, what are the most important things a liver does.

Nicole Wells 2.32

So, the liver does a lot of important things, it actually has over 500 vital functions. And some of the main things are regulating blood pressure. So, if you have cirrhosis, you will likely have low blood pressure if you take it with the cuff normally, although internally a different story is going on, it also makes your platelets go through your spleen.

So, if you have end stage liver disease, you will likely bleed a lot easier. And it is attached to the heart and the pancreas so that's another reason why it is so easy to lose blood during liver transplants, because there's so much blood flow. So it does a lot, but those are some of the main things, including filtering out toxins. As you know, maybe after a long night of drinking, you might not feel the best and all of that poison essentially is still in your body. So, if your liver doesn't work properly, then really any sort of poison including ammonia and meat, it is going to have trouble being processed correctly.

Jennifer Cohen 3.49

Okay. Now you've already brought up cirrhosis and I think most people are familiar with the idea, as you've just

pointed out that abusing alcohol can cause the liver to have problems. People know about liver cancers. What are some of the other diseases that can affect the liver?

Nicole Wells 4.06

So, there are over 100 liver diseases and most of those are rare. So, you mentioned alcoholic cirrhosis, viral hepatitis. There's also fatty liver disease or steatohepatitis, which can lead to NASH or cirrhosis from fatty liver that is becoming much more common, unfortunately. There are also autoimmune diseases that attack the liver, such as autoimmune hepatitis or primary biliary cholangitis. And since there are so many different liver diseases, and they are so misunderstood, whenever you have a disease such as autoimmune hepatitis, people make assumptions because they don't know what it is. So that's one of the reasons why it's so important to become educated and learn about these things so that you can understand one another better. And hopefully, none of the listeners will be in this situation in the future. But if you are, at least you're a little better prepared.

Jennifer Cohen 5.14

Right? And hepa-, that prefix that's for anything to do with the liver.

Nicole Wells 5.21

Right? Yeah.

Jennifer Cohen 5.22

And hepatitis is basically inflammation of the liver.

Nicole Wells 5.25

Yep. And liver doctors are called hepatologist.

Jennifer Cohen 5.29

Okay, very, very good. Thank you for that. Okay, when something starts to go wrong with the liver, what are the usual different options people face? Can there be drug regimens? Surgery? How is that usually addressed when something starts to go wrong with the liver?

Nicole Wells 5.47

So, it depends on the specific liver disease. A lot of times, you can even have cirrhosis and not fully know that you have it. If you start itching a lot, that could be your liver. And you might go into a dermatologist to try to seek treatment for that without knowing that your liver is causing it. So, one of the best things to do is to get your liver

labs checked regularly and see if there are any abnormal numbers there. Just keep an eye out for liver symptoms. I said itching was one, jaundice is another, fatigue, and not many people know this, but depression can also be a symptom of liver disease.

Jennifer Cohen 6.36

Wow. Okay, let's now turn to your story, which began long before you made the decision to have a liver transplant. What were some of the health issues that you were dealing with and when did they start?

Nicole Wells 6.51

So, I first went to the doctor regarding my liver disease whenever I was 15, but I didn't know it was for liver disease. I actually went into my primary care physician for strep throat. And I was ultimately diagnosed with strep throat but based on some of the symptoms that I was experiencing, such as extreme fatigue, I would fall asleep as soon as I got home from school, and I would fall asleep in class, I was just sleeping all throughout the day, my internal clock was reversed, that's also another symptom, and I was having back pain. So I went to a back doctor, like I said, some of the symptoms can be misinterpreted for another sort of disease or disorder. So, they took my labs, and I went home, you know, with a strep throat diagnosis, and I didn't really think anything else of it. But then the doctor called back the next morning, and they were obviously very concerned. So, they asked for, of course, my mom was with me at the time I was 15. So, we both went back in that day and had an ultrasound and then immediately they could see that my liver was very cirrhotic and it was end-stage and they could see that immediately. So, at that point, the next day, they brought my dad in and they were still doing bloodwork throughout this whole time. So, at that point, they said you're going to need a procedure early next week, it's a needle liver biopsy and because of the state of your liver, we can't give you anything, no pain meds, no Twilight, nothing at all. That was, I guess, kind of my first big medical procedure and that came out inconclusive, unfortunately. So, like I said, I live in Kentucky, and I went to another specialist here. And by that point, it was just maybe two weeks in and my stack of medical records just from those two weeks, several inches thick by that point, and he didn't really know what was going on. It was mysterious. So, he sent me to Cincinnati Children's, and luckily they were able to get me in, they have their special liver clinic cases on Wednesdays, they had a spot open, thankfully and they got me in there. And they did another surgery at that point that one was called an open surgical wedge they had to cut me open a good amount and take even larger pieces of my liver out to try to see what was going on there. And it was still inconclusive. So, you know more tests and things like that and they eventually said okay, well, let's just put her on prednisone, just in case it's autoimmune hepatitis, then hopefully that will help. It did turn out to be autoimmune hepatitis. But then they did some more tests, which is basically an MRCP, which is an MRI of the bile ducts. And through that, they found out that I also have another rare liver disease, which is primary sclerosing cholangitis that attacks the bile ducts. So those were my diagnoses. Yeah. So that whole time, I was glad that I finally was able to receive a diagnosis. Autoimmune hepatitis, it has no cure, but it does have a treatment, a bunch of prednisone and chemo. But with primary sclerosing cholangitis, there is no treatment that is FDA approved a least and no cure. So average time from diagnosis to death, or liver transplant is approximately nine years with primary sclerosing cholangitis. Unfortunately, liver transplant is often seen as the only treatment, we definitely need more drug development and approval in rare diseases.

Jennifer Cohen 11.18

Yes. Those were very tough diagnoses you received; how did your life play out then as a 15 year old through high

school?

Nicole Wells 11.29

During that whole beginning time, I couldn't go to school, I was pulled out, I was on a homebound and I was in all AP classes, and was doing some pretty rigorous academic work, at least at the time and I appreciated that. But once all of this started happening, my teachers know that fractions and European history and everything, those don't matter whenever you're dying, especially at such a young age. I didn't really learn that much in terms of formal education during that time. So, I was able to kind of do my own education and seek out what was interesting to me. So that was good, at least, a lot of my peers, they couldn't understand what I was going through. Unfortunately, while I guess, fortunately, but most people don't really start to have to grapple with those sorts of things about the fragility of mortality until they reach an older age. So, I was thinking about those things a lot and, you know, having to deal with really serious things and some of my peers were also, but they weren't the same thing they didn't understand. That was hard, it was isolating. And eventually, I was able to go back to school, thankfully. So, I had my whole senior year, I would sometimes have to, you know, miss, so I had a standing doctor's notes. And, you know, I was still having to go to the doctor a lot and having random hospitalizations, random, near-death experiences, but that was just my life. And then once I got to college, I originally went to college out of state in Virginia. And something I regret not doing, that I would not advise anyone with a rare disease to do, is I did not tell my professors, I did not go to the disability office, and I wasn't really that open about my conditions. Of course, I get sick a lot easier than other people. And so sometimes I would have to miss things like that. And I just should have been more open about that. I was able to graduate college, I even did a study abroad, I think it was my junior year. And you have to get medical approval to do that so I took the form to my hepatologist he was concerned about me even flying because whenever you have end-stage cirrhosis, you can have a side ease, which is the fluid retention. That's why if you see someone who has end stage liver disease and my look like they're pregnant, and then the other one is varices. So, whenever your liver can't filter out all of the blood and toxins and everything that it needs to do properly, the blood will eventually start to form other pathways in your body, but they're not natural. They're not supposed to be there so they're fragile, they can easily burst and then you can bleed out So, my hepatologist was concerned about that occurring on the flight because of all of the pressure up in the air. But eventually he let me go because life is for living. And, of course, I had a hepatologist there, but I did have another near-death experience there in Milan. And I thought I was going to die alone, where no one even spoke my language. And I didn't know anyone that wasn't great. But eventually, I was able to return to health, and come home and graduated college. By that point, I went into grad school right after I graduated college. And because of all of my experiences, I want to make sure that I'm happy with the way that I'm living my life that's important to me is I don't want to look back and have any regrets. I think about that periodically, and just kind of have a personal check in with myself, the first year of grad school, I came to the conclusion that this isn't what I want to do. I don't want to pursue academia as a career, I don't want to stay on this path because I'm not helping people enough. So, I was starting to think about a career change and what that would look like. Then I took this discover scuba course in Cincinnati at the YMCA, there is a groupon for it. I went there with my friends, and this is very dramatic, but it changed my life because I realized how much of the world I'm missing out on by just staying on land the entire time. So I, once again, went to my hepatologist and had the medical approval form. This time, he said no, because once again of the varices, he was concerned about that underwater, he was like there's a good chance that you would bleed to death underwater, it's not worth it. But that point, I knew I was drawn to the ocean, I couldn't scuba dive, so I still wanted to be closer to the ocean, and like I said, I was living in Kentucky still at the time. I had my teaching certification from undergrad since that's what I studied. I started looking at certification and the territories, got my certification and in Guam, and then the Virgin Islands, applied for jobs there, and ultimately, I decided on the Virgin Islands. I went there, I sold all my stuff and then moved there within

two weeks. It was fantastic. I loved it, but my health still wasn't super great. I was still having to miss a lot of work, my body takes longer to recover, or at least it did or just wasn't working out, unfortunately. So I moved back stateside and eventually I was listed for a liver transplant.

Jennifer Cohen 18.39

That's such an incredible story, Nicole, of getting through your education and starting a career. Thank you for sharing all of that. So honestly, and it's really inspiring how much you were able to do and willed yourself to do. Before we get to the decision to get on the liver transplant list. Let me take a short detour on one issue. When you turned 18, when you talked about going and getting these medical releases and stuff, you'd been with the pediatric liver world for a number of years, and then you were transferred into the adult liver world. Was that a tough transition?

Nicole Wells 19.17

Yes, and in my case, I actually was still at my pediatric hospital whenever I was going through the process of being worked up for transplant. Yes, that was difficult and a lot of people with rare diseases they will sometimes stay at their pediatric hospital for a little bit longer just because that is someone who knows what to do with this specific disease and that can be difficult to find sometimes. Yes, whenever I needed a transplant, that's whenever my pediatric hospital said unfortunately, we can't transplant you here, we would be comfortable with it as far as the hepatology team, but there are so many other teams involved. And this is a pediatric hospital that we can't do that it was then that I had to transition into adult care. Unfortunately, I felt like I was kind of thrown to the wolves, because they didn't really help me find an adult Transplant Center. Unfortunately, a lot of people might feel that way because that transition from pediatric to adult isn't where it needs to be overall. Yeah, that was that was really difficult.

Jennifer Cohen 20.38

It seems like an overlooked area. for patient care, this transition, it'd be worth thinking about, I think, from bioethics and the medical world and how to make the transition easier for people. So, when you decided to get on the transplant list, was this you seeking that option out? Or was your medical team advising you to do that, at that point?

Nicole Wells 21.00

A little bit of both. I was 24, at the time, about to turn 25 and I was going to go off of my parent's insurance. At age 26, I had end stage liver disease, unfortunately, you can't receive a transplant in the United States of America without health insurance that was required. So that was something I needed to start looking at anyway. But really, it's really hard to determine, especially with rare liver diseases, how sick you truly are because the MELD score, which we'll go into later, it is an inaccurate representation of your liver health overall.

Jennifer Cohen 21.52

Let's talk about that now to get on a liver transplant list, the medical criteria that centers around, as you've just stated, this MELD score model for end stage liver disease, what is that? How is it determined? And I'd love to hear your thoughts on why that is not the best way to assess readiness for a transplant.

Nicole Wells 21.11

Yeah, so basically, it is a very simple calculation. So, all it requires is your bilirubin levels, serum sodium, serum creatinine, and then if you have had dialysis twice within a week, prior to this test, and as long as you are above age 12. That's all it takes to an account, and that is supposed to determine how long you have left to live basically, with the condition of your liver. Typically, that is how you are prioritized in terms of the liver transplant list.

Jennifer Cohen 22.51

So, it's not so much a matching process, it's more predictor of survival?

Nicole Wells 22.56

Yeah, that's what it is. And it does not really accurately portray the severity of women's disease, there's definitely a sex-based disparity, things like height, all of that should be considered whenever calculating something as important as a number that determines who will receive a lifesaving organ.

Jennifer Cohen 23.25

So, you've got the MELD score, that determines whether you will be listed and where you will be on the list, and then there are allocation regulations by UNOS. The United Network for Organ Sharing, which is a nonprofit that sort of runs the organ allocation system in each state and nationally, how does that intersect with the MELD score?

Nicole Wells 23.52

You know, they are like you said a nonprofit, the government OPTN pays them so there is this partnership and that's how UNOS makes all of these policies. The center, they have their own policies as well and they can really determine at what MELD score they will list people at. So UNOS, they provide the MELD calculator, things like that. There are also ways to get exception points that UNOS, will, they'll regulate that. So, the center has to go off of everything that UNOS says, but ultimately, they get to decide who they list for transplants. Some of those things include age, if you're over 70 years old, it is probably going to be difficult to receive at least a liver transplant and most centers. One of the reasons why I couldn't receive a liver transplant in Kentucky was because there are two centers here and they both do deceased donor liver transplantation, they don't offer living donor liver transplantation. I was 24 at the time, as you know, and like I said, it can be difficult to determine how sick you really are, especially with rare liver diseases. I was encouraged to wait. Even though I qualified to be listed by everything that the center required to be listed, my MELD score was accepted, things like that, they still wouldn't list me because they wanted me to basically wait as long as possible beforehand, so that their idea was that the transplanted liver would last longer too. Just in case I eventually develop cirrhosis on this transplanted liver.

Jennifer Cohen 25.57

Okay, so unlike heart donations, liver and kidneys can come from living donors, as you're describing. So, you decided then to seek a living donor, rather than wait on this transplant list? Can you talk about your decision to seek a liver from a living donor, and how that played out?

Nicole Wells 26.20

That was, by far the most difficult decision of my life. You know, in order for me to live, someone else had to either die or suffer. It can be difficult for people who receive organs from deceased donors because there is that survivor's guilt, of course, but at the end of the day, you know, that person didn't die specifically to provide their organ to you, but that is a heroic moment and a great gift. With a living donor, of course, they are going into this and suffering because of you. For me to decide that I took a lot of time it took a lot of thinking about it, but I ultimately decided because I would be interested in being a living donor. So, I know that if I am then other people probably genuinely want to do that. I'm going to accept that. And like I said, I was going to turn 26 and I couldn't really wait around even though I was lower on the list. I still was too sick to go to work or go to school. I was 24 years old, couldn't get out of bed most days, so I wasn't really living a productive life and I was ready to move on with my life. My sister, she was ultimately a candidate, but we didn't know that at first because I talked about fatty liver previously and she was diagnosed with fatty liver whenever she was 19 years old. So, we thought that she was ineligible because of that, and she didn't get tested or anything because we were still operating under the assumption that she still had fatty liver disease. Other people were getting tested for me and going through that process. When all of a sudden, her gastroenterologist called her up. She said, I can't stop thinking about your liver, Katie was like okay, you know, and her gastroenterologist was like, I want you to come in and do an ultrasound and get some blood work. I don't know why I'm just I can't stop thinking about it. Katie has celiac and that's why she goes to her GI. She wasn't expecting a call from her anything that wasn't normal. So, Katie went in there, she got her bloodwork and ultrasound, and her liver was completely healthy. And this gastroenterologist had no idea that she had a sister on the liver transplant list who needed a living donor. That was amazing.

Jennifer Cohen 29.17

Incredible, wow.

Nicole Wells 29.19

Yeah. So, then the next step was to find out if she was the same blood type as me because I'm O negative. Thankfully, Rh factor doesn't matter in organ transplants, so I could have accepted someone with an O positive blood type. But we found out Katie was also O negative. She was basically a perfect anatomical fit for me. That's pretty amazing the way that it worked out.

Jennifer Cohen 29.45

How old was she? At this point?

Nicole Wells 29.47

She is two years younger than me, so I was 25 at the time of the transplant and she was 23.

Jennifer Cohen 29.54

Wow and the wonderful news is that the transplant went well, both of you are healthy. The liver has this incredible ability to regenerate. Can you talk about how that works in both the donor and the recipient?

Nicole Wells 30.08

The liver, as you said, as two lobes, the right lobe is a little bigger, and then the left lobe is a little smaller, you can technically live with up to 80% of your liver taken away, so you keep 20%. But transplant centers usually will not take more than 70% of someone's liver to donate so you cut it down between the lobes and the donor keeps typically the smaller half, it depends on their size proportions, and then the recipient typically takes the larger half. Then within a matter of weeks, they both grow into two full livers. You can live with that for the rest of your life.

Jennifer Cohen 30.58

Incredible.

Nicole Wells 30.58

Yeah, you can't donate it though after, after you donate your organs upon death, unfortunately, like you could potentially with a kidney. But with a separated liver lobe you can't.

Jennifer Cohen 31.13

Incredible. Okay, let's talk about now some of the post-transplant issues which will actually I think circle back to some of the issues you raised in the lead up to this. Do you still have the autoimmune diseases that you were diagnosed with? How does that work now that you have a new liver?

Nicole Wells 31.34

There are some diseases that once you have a liver transplant, you're cured, example of that would be Wilson's disease where your body your liver has trouble processing copper. So, if you have a liver transplant, and you have Wilson's disease, you don't have to worry about it anymore. But for my specific diseases, the autoimmune hepatitis and primary sclerosing cholangitis, those could potentially continue to attack me, so I have to be extra immunosuppressed. Whereas if someone had alcoholic cirrhosis, or fatty liver disease, they wouldn't have to be as concerned about that coming back. With this extra immunosuppression on top of the normal immunosuppression and regular checks. Yeah, you just basically have to hope it doesn't come back.

Jennifer Cohen 32.29

Okay. Let's talk about some of the mental challenges because you had, starting at 15, getting the transplant at 25, that's 10 years of what you described so movingly of isolation and confrontation with some of the most difficult aspects of living, which circle around mortality. How did the transplant help with those issues? Do you still have ongoing PTSD, for lack of a better phrase with those issues? How has the transplant affected your mental health?

Nicole Wells 33.09

So, I think that pretty much everyone who has a liver transplant and has PTSD, whether or not they realize it, then the caregivers do also. But my anxiety got a lot worse after transplant and that is because the medications actually have anxiety as a side effects. That is pretty common, and it's pretty bad, so I take medication for that that helps. Then my depression, so after my transplants, I eventually returned to Kentucky after I was cleared to return home, I still had to go back to Baltimore, about once a month for a while, which was pretty stressful trying to figure out how to get there, especially since I didn't have a job or income at that point. At that point, I was hoping that I would be able to go back into society and contribute. But it hadn't happened at that point, so I continue to feel like a burden, and I felt like that for a long time until I was able to get a job and start living my life again. But unfortunately, not everyone is able to do that, some people have to remain on disability, or you know, just do what they can to survive still. And so, I'm really, really lucky that it was turned out the way that it has for me.

Jennifer Cohen 34.43

You mentioned Baltimore, so you had the transplant in Maryland. Did you and the family relocate there during that time?

Nicole Wells 34.51

Yes, and I'm very grateful for them as well. So I have an amazing support system, my parents went and I have three younger sisters, two of them were still children at the time. And then Katie, my sister who gave me part of her liver, obviously she was an adult, but she had to be there. So we all went, my boyfriend at the time we weren't engaged or married or anything, and because of that, he couldn't take time off of work. So, he saved up all his vacation days and he had a week of vacation and he spent that by my hospital bed and the ICU that whole time and he didn't leave.

Jennifer Cohen 35.36

Amazing.

Nicole Wells 35.37

Yeah, then he had to go home and I was still in the hospital after that. Yeah, I had a wonderful support system so I'm so grateful because if you don't, if you don't have anyone. That's another barrier to transplant, they won't transplant you then.

Jennifer Cohen 35.53

You need the social support.

Nicole Wells 35.56

Definitely, you need 24-hour care.

Jennifer Cohen 36.00

And you mentioned the necessity to do this before you came off of your parents' health insurance. Have you faced financial challenges post-transplant, in addition to the physical and the mental, ongoing challenges?

Nicole Wells 36.14

It took me a while to get to a place where I could go back to work. And then once I could, you know, the medication, sometimes I will have side effects that are less than ideal, such as diarrhea and things like that. So, I might have to go to the bathroom a lot, or I still might get sick, easier than most people. So my first job, whenever I got back into the workforce after transplant, they weren't very understanding about that they didn't honor my request to work from home some days, even though I could. But thankfully, now I work for Global Liver Institute and I work remotely and they're very accommodating, so I'm lucky to have the employer that I do.

Jennifer Cohen 37.04

Okay, perfect segue into yet another remarkable aspect of your young life that you've taken all of this experience and turned it into advocacy. Tell us about your work at the Global Liver Institute, what that does and what you are doing there.

Nicole Wells 37.19

So, I started volunteering for the global liver Institute, or GLI just a few weeks after my transplant. I was living in Baltimore at the time and GLI is based in DC. There is this Advanced Advocacy Academy or A-three every fall, it was three weeks after my transplant, and I had heard about it from a Facebook friends. I was interested in going you know; I didn't have anything else going on besides recovery. And I wanted to do something meaningful. So that was definitely some of the worst physical pain I've ever been in was sitting up that long after transplant, but everyone was really great and accommodating. And from there, I started getting more involved and getting more involved with other nonprofits. Then I was hired on by GLI full time in September of 2020 to launch their pediatric and rare liver diseases council. So, I'm really glad about that. And we are focusing more on pediatric and rare liver diseases, which is great. We just had rare liver diseases month in February and this month, I'm actually moving departments to Advanced Advocacy Academy so it's kind of come full circle at this point.

Jennifer Cohen 38.43

Wonderful. Okay, let me pick your brain now on three policy issues around transplantation in general that I'd love to get your thoughts on. In January 2022, headlines were made when the first transplantation of a pig's heart into a human took place at the University of Maryland. This heart had come from a one-year-old genetically modified pig, genetically modified using the new CRISPR technology to knock out genes that would be harmful to humans and then to knock in genes that humans need around inflammation and blood coagulation. And this pig had been raised at a facility of the private company, Revivicor, it was implanted into a 57-year-old man with heart failure. It made headlines all over the world and there was a New Yorker article profiling the surgeon and quoted him as saying it was one of the best hearts I've ever seen after transplantation. And I think there have been two or three successful pig kidney transplants. This whole field is called xenotransplantation, this whole field of using animal organs for transplantation into humans. What do you make of this? And what are the ethical issues that you see?

Nicole Wells 39.59

Right, so I see quite a few ethical issues. First of all, pigs cannot consent, so there is no way that we can be sure that they are okay with this. Pigs are so intelligent, they're smarter than dogs and toddlers, so we wouldn't take a kidney or a heart from a toddler or an infant who's alive, even though they can't communicate. So, we're doing that with another species just because we don't understand them. I would love to see these resources and all of this attention and science being put towards 3D printed organs instead.

Jennifer Cohen 40.47

Yeah, talk about that. That is, I think of 3D printing as something that produces something plastic, but it is being used to create organs using cells around a sort of plastic scaffolding that then disappears, and there is hope for this. How is that moving along? Do you know where the science is at this point?

Nicole Wells 41.08

Basically, that is definitely promising. It's using cells to create these organs. One of the biggest problems is figuring out blood flow. Blood flow is really important in certain organs, all organs, but especially the liver and being able to replicate that is difficult. So, it will still be a few more years, but I'm hopeful.

Jennifer Cohen 41.37

Okay, and another issue that's been in the transplantation world for a while now is opt in versus opt out systems. Systems, like they have in the US where there is no presumed consent to be a donor, you have to expressly consent to be a donor. And in many cases, that means going to the deceased person's family, and obtaining consent, and opt in systems where there is presumed consent for being a donor, unless someone expressly opts out. The issue that's always brought up is that I think the Department of Health and Human Services did a study a while ago that said something like 95% of Americans were in favor of organ donation, but we sort of tap out at about 60% of the population signing up to be a donor. So where do you stand in this opt in versus opt out system debate?

Nicole Wells 42.39

I used to be in favor of opt out, because like you said, 98% of people in the USA are in support of organ donation, but only about 60% are registered donors. But due to the prevalence of misinformation in our culture, I think at this point, it is better to have opt in because if you have opt out, then that's it. But if you aren't a registered donor, you could still potentially donate your organs if your family chooses to do so.

Jennifer Cohen 43.21

Right. Yeah, so yeah, I think it is not clear that either system registers the number of donors. So you know that there's such a difference between the success rate, that this is why it's still clear that there are underlying sort of cultural barriers to organ donation that seem like they need to be addressed. And that just changing the opt in opt out. rules might not be enough.

Nicole Wells 43.49

Definitely. Yeah, exactly there are so many other things that need to be addressed first. There are a lot of viable organs in the USA that are unfortunately being discarded, that we could use, we could also split livers into halves and transplant two people at a time instead of one. We could increase the prevalence of living organ donation. There are just so many other things that we could do.

Jennifer Cohen 44.22

And my last question, Nicole, how well do you think the United States is doing in addressing socio economic obstacles to transplantation? You've already touched on this and you're bringing up now even medical obstacles to transplantation that could be addressed. But in terms of socioeconomic obstacles, how do you think the medical world and the United States in general, public health is doing?

Nicole Wells 44.50

Well, first of all, you can't have a liver transplant or an organ transplant without health insurance, so offering Medicare for all, and ensuring that everyone does have access to health insurance would be probably the biggest thing that could be done immediately to eliminate some of these barriers. There is also making sure that there is the funding available so that hospitals can have the resources to create living donor liver transplantation programs. They require double the teams double the equipment, everything, so a lot of centers, unfortunately don't have the resources to implement those sorts of programs. Offering caregiving for people and having that available as a service would also eliminate some of those barriers. And of course, addressing racism is a huge one as well. A lot of people have mistrust in the medical system, due to a history of racism that is still occurring today, unfortunately, so addressing those as well could help.

Jennifer Cohen 46.12

Nicole, thank you so much for sharing your incredible story with us today. And thank you for all the work you're doing on behalf of patients everywhere. Good luck, best of luck to you in the future as you carry on this incredibly

important work.

Nicole Wells 46.28

Thank you so much, Jennifer. It's been great talking with you.