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Dr. Dean: Thanks very much, Joe. And thank you all for zooming in to join this breakout session. It's my privilege to give this sort of talk to this group of patients and family members. It's really one of the highlights of my year honestly because this group is so engaged and so proactive about their own health care and that of their family members, it's refreshing to me.

So, today I'm going to talk about kidney transplantation. There will be plenty of time for questions and answers at the end. I think I'm a transplant surgeon so I'm not probably the best person to ask about what foods to be eating or you know when to start dialysis, that sort of thing. But I can give those things a stab. But I'm again, I'm not expert in those areas. But today's talk is really meant to give you guys a sense of how to get ready for a kidney transplant what the transplant entails and what sort of to expect. Now there's some sessions, maybe one going on right now about living with a transplant and how to manage that after but today is really about getting going and how to prepare for a transplant.

So, we'll get started with the slides. I have no disclosures of any sort of relevance to this talk. And then this is the activity disclaimer from the foundation that you'll probably see with most of the talks.

So, first, we need to think about when we should start preparing for kidney transplant. And I think a good rule of thumb and it might vary per individual, but it's probably some when your GFR and those of you who go to clinic and have your creatinine measured by a nephrologist will know and this is just a calculation based on the creatinine and a few other factors. Probably when it's around 30 is the time to start thinking about a transplant. Doesn't mean you're going to need one next week or next year even or even in a few years. But it's a good time to start thinking about it. At least starting to wrap your head around what can be a really big thing to wrap your head around. It's a big deal.

You can't be listed until your GFR in that's either calculated or measured is 20 or less. So, if it's 21 or two, and that's the lowest number you have you technically cannot be listed for a transplant. One misconception I think that we see not so much with this group, but with some other patient groups, is

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that you don't have to be on dialysis before being listed or before receiving a transplant. You know, we do think in general, it's best to receive a pre-emptive kidney transplant or a kidney transplant before you start dialysis. I know Dr. Clifford Miles from the University of Nebraska is giving a session on that tomorrow that may be worth listening to. Clips of very good nephrologists out there. Another Midwesterner but does a really nice job with PKD folks.

And it's really for several reasons but you avoid the dialysis if you can. That's no fun for sure the dialysis whether you're doing peritoneal or hemo. And we do know that if you're on dialysis for much longer than a year, each additional year that you're on dialysis before transplant means your predicted survival after a transplant is going to be less. So, if possible, it's best to receive a transplant before starting dialysis. Now, that doesn't happen, in the majority of cases, if you look at all the transplants in the country, only about 30% are done in a pre-emptive manner. If that, probably even less now.

So, in order to have a transplant, you need to go through what we call a transplant evaluation and what most centers would call that I think, and just as an aside, some of what I talked about will be very generic and should apply to most transplant centers. I will try to refrain as best I can from very specific things related to our center. And I don't, because it's everybody's not able to come to where we are and there are 250 odd kidney transplant centers in the country so. But in general, the process is fairly much the same. That evaluation depending on where you go, depending on how much they group together can be anywhere from two to three days at that center or some space it out more. Certainly, if you live across the street from the center, there's no reason not to space it out.

And the evaluation means meeting with a nephrologist. You'll meet with a transplant coordinator; you'll meet with a social worker you meet with a surgeon. And that's sort of the basics you'll meet with a pharmacist too and then also some transplant financial people to go over your insurance and your costs or potential out-of-pocket costs. And of course, there are other tests needed some patients need to see cardiologists because of heart issues. Some

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need to see psychiatrists because of mental health issues, for example. But that's it's pretty comprehensive and sort of I call it 100,000-mile checkup because it's very thorough, and sometimes you find some things.

The medical side of things really focuses on will you benefit from a transplant and that essentially means do we anticipate you're going to live for a while after receiving a transplant, for patients with PKD that's generally fairly true. Many of you and your family members are, you need a kidney transplant because your kidneys are sick. Not because you're sick all over and that's affected the kidneys if that makes sense. The heart is something we focus a lot on, and you can see really severe cardiac disease is not terribly common in people with PKD but can happen especially in smokers or those with other conditions. But really, it's uncommon to have a condition that really would say, you're too sick for a transplant and PKD population. But what we do occasionally identify things that will say, we need to fix this or try to get it as optimized as we can before we proceed with the transplant.

Specific things we often look at for patients with PKD are aneurysms or enlarged blood vessels in the head and inside the arteries that supply the brain that tends to run in families within PKD candidates or families. And then that's usually screened for with an MRI of the head. And occasionally that we identify those that need to be dealt with before transplant to prevent strokes. Many patients with PKD are almost all really will have some number of liver cysts. The question is how big they are. And if they're really symptomatic, rarely, we'll refer patients, or they will have come to us through our liver transplant clinic for cystic liver disease. And then and we'll talk about this a bit more later is the need for what we call native nephrectomy or having your old kidneys removed at the time of or in preparation for a transplant.

The surgery evaluation usually this is one of your shorter visits at the clinic, but it focuses on your any prior transplant you might have had prior to operations on your native kidneys. And then we really examine the abdomen fairly closely. Taking a good inventory of the size of your kidneys any prior transplant incisions or other operations and then we take we feel your pulses

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down into groins with us with arteries that we use to sow the new kidney and to up a little higher, but if they feel good down in the groins, and they're nice and strong, then generally that's an indication they'll be good upstream.

The psychosocial evaluation and this is generally conducted at each center by a social worker. And we're really looking for severe things that might preclude dealing well with a transplant or dealing well with the regimen of medications and that sort of thing afterwards, people with, you know, schizophrenia, severe mental illnesses, sometimes we have to turn down but not very commonly, we'd like people to not have significant dependence on chemicals, especially illicit drugs and or alcohol. The social workers will talk to you about what kind of support you have and how you'll be able to pay for some of the out-of-pocket costs. People with good insurance, generally there not a tremendous amount of out-of-pocket costs. But there are some, whether it's just traveling to your transplant center, or whether it's paying for some of the co-pays for the medications, but the social workers are fantastic about working with you on that.

Very common for folks to come to have the evaluation and then they're really raring to go and then get listed or proceed with a living donor transplant. These are the sorts of things that might delay things or prevent ultimate approval for transplant. Cancer is a very broad term but people with active or very recently diagnosed and treated cancers of certain types, we tend to have a waiting period for before we do a transplant and other things that in this isn't very common in our PKD populations. But people with a chronic illness say maybe you know bad emphysema or something like that or really bad heart disease that would really predict you're likely to die within the next few years, it's probably not the best thing to go forward with a transplant. As we mentioned, poorly controlled mental illness is an issue sometimes, but not very commonly.

Severe obesity and each center you'll visit with will have sort of their own criteria for what they consider to be too obese, perhaps a list for a transplant or approved for a transplant. That will vary across the country at different places. Most places will have a Body Mass Index cut off of somewhere

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around 35 for Body Mass Index and ours happens to be 40. But it depends on the center, and we recognize body mass index is not a perfect way to estimate obesity. The ideal way would be to put everybody in a water tank and measure their percent body fat but it's one way that we can easily calculate things, but it can misrepresent some people's body fat and muscle distribution.

Rarely, we see folks that can't remember to take their medicines. But that doesn't mean people with fairly significant mental challenges can't receive a transplant if they have good caregivers. As I mentioned, you know, current drug or alcohol abuse. And then occasionally, and again, this isn't very common in our PKD population and the folks we're able to see, but people that just really don't comply very well with medical treatments, and on their dialysis, they skipped dialysis quite a bit. And just perhaps won't, because you're getting a transplant, it's not a cure, and it's trading one condition for another, but you need to be able to participate in with your team and follow the recommendations.

How do you best prepare for a transplant, I think it's like preparing for any sort of surgery. And I think if you really the long and short and you want to be in as good a shape as you can going into it. Increasing your physical activities good to help you prepare for the anesthesia, people that are fit and a little more active going into any type of surgery tend to recover a little better. The next few the low sodium diet and the saturated fats are more just good general advice to any of us, especially those with kidney disease. Ideally, people are able to abstain or stop using tobacco. And that generally, you know, there are negative effects of both vaping and smokeless tobacco, cigarette smoking and tobacco and cigars are probably worse from the effects they cause on the lungs. But there are sort of, there can be bad cardiovascular effects with tobacco use in general.

And then if you find yourself in a category that you think you might want to lose some weight, we would recommend that. And that's one to minimize your chances of any incisional or surgical-related complications at the time of the transplant. And really long term, you know, 10-20 years down the road

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to improve your overall health and minimize the chances of developing things like diabetes after the transplant, or significant heart disease or cardiovascular disease. And this is, I'm not again, a dietitian. But a good way to lose a pound or two a week, which is probably what many folks consider to be medically safe and not too drastic, would be to eat around 1500 calories a day for most men. And that's this is fairly general. But depending on your size, it can vary, and about 1200 calories for women in order to lose about a pound or two a week. And so that can be helpful going into things.

And again, these are the reasons to improve your condition or prepare for things. And that's why it's nice to start when it's around 30 or so because you have some time. Rather, it's not going to be an emergency. So, we do recommend you get in as good shape as you can knowing that that's not always possible because sometimes you feel miserable.

Generally, there are two types of donors for kidney transplants. One is a living donor kidney. And that can be a relative, it can be a friend, it can be a church member, it can be an acquaintance, it can be somebody that in your community that from church or from work that decides they're interested in donating a kidney to you after they hear your story. And then there are deceased donors. And these used to be called cadaver donors, but now the term is deceased. And those are from donors that are either brain dead due to some catastrophic neurologic insult, whether that's a trauma in a car accident, or whether it's something like a stroke or a drug overdose. And then there's what we call donation after cardiac death where the patient isn't able to be declared brain dead, but they've suffered a what is deemed to be sort of non-survivable injury or their outcome is such that their prognosis is quite poor. In that case, their support is withdrawn and then the organs are harvested in a relatively quick fashion in an operating room.

If possible, we are really big fans of living donations. And the reasons are really three, if not four, but and we recognize also that everybody doesn't have a potential living donor. Especially in some PKD families, the members of the family that aren't affected by the genetic mutation many times have donated to another family member. And so that kind of narrows the donor

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pool, at least within the family. But if you can and are able to find a living donor, we can oftentimes do the transplant before you need dialysis.

The waiting time, I say no way, that doesn't mean that you're approved, and the donors have proven that you do the transplant the next week, you may not need it the next week. But the waiting time will depend on where you live in the country or more specifically, where you're listed for transplant in the country. Here in the Midwest, if your blood type is O, average waiting times are about five to six years. And that's just one example B is a little bit longer, A is a little bit shorter. If you're on either coast where there are many, many people waiting, these waiting times can be 10 to 12-13 years, so quite a long time.

In general, living donor kidneys tend to function immediately, meaning they start making urine as we're right after we saw them in, you don't need to do any dialysis or experience what we call delayed graft function, which is happens in about a third of deceased donor kidneys, it doesn't mean they won't work, it just means that you might need to do some dialysis while the kidneys recovering in a deceased donor situation. And then in general, living donor kidneys tend to fare better long term. And that's mostly because we know a lot more about the living donors, I think it's not I mean if everyone received a kidney from an 18-year-old, deceased donor, or a 25-year-old, or some very young healthy donor that we knew a lot about there probably wouldn't be a difference. But I think, you know, we do such detailed testing in the living donors that probably accounts for most of the difference in these survival curves. And they're not too far apart early on.

And the way we define graft survival or survival of kidney is that you either you have not returned to dialysis or started dialysis, or you haven't had another transplant. But if we look at 10 years, 63% of the living donor kidneys are still functioning, and these are national data. And then compared to deceased donors, and that's around one in two. So, but the difference in it gets a little larger as you go farther out. This is sort of why the waiting times are quite long. There were when I finished putting these slides together a month ago, there were about 90,000 people in the United States waiting on a

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kidney. Last year was the biggest year of deceased donor kidney transplantation ever. And there were, you know, 18,699 done. So, you know, that's 70,000 short. And that was the biggest year ever for a deceased donor kidney transplant, there were just under 6000 living donor transplants done.

Just as a matter of perspective, polycystic kidney disease patients account for about 6% of those patients on the waiting list than that's more just it doesn't mean you have any work more or less priority in the waiting list. I just think it's nice to kind of know what proportion of folks in the country have it. Again, these are our waiting times I mentioned five to six years for O, four to five for A, six to seven for B, AB wait less, but it's not real short still, it's still two to three years. So, it can be a really long time, much of which might be spent on dialysis.

One question that we encounter a lot in clinics when we talk about deceased donor kidney transplantation is should I be listed in multiple places, meaning multiple transplant centers? So very good question and it's a complicated answer and it keeps changing. So, but as of last year, the way kidney and hopefully you can see me outline, this is where we work. This is called region seven. And so that includes Minnesota, North Dakota, South Dakota, Wisconsin and Illinois. What used to happen is that if a kidney were here in Fargo, North Dakota, which is about there, that kidney would first go to people in our little three state area. If no center accepted it there, then it would go to the region and then it would go out nationally. And what you'll notice that after considering a lot of different models is that they removed that sort of local boundary based on map lines and things and we've many or many other organs did this too. In fact, all the other organs did this.

It's based on sort of the distance between where the candidate, meaning that kidney transplant candidate is listed for a transplant. And so that Transplant Center and where the donor hospital is. And this is just an example, right out in the middle of the country. And the number that we use for kidneys is 250 nautical miles, why they chose nautical miles, I don't know. But they're not exactly the same as normal miles. It's about 1.3 normal miles. But as an example, and so there, if you're listed at the center, where the donor is, for

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example, and this graph depicts that you will get two extra points. So, if that donor is at our hospital, and you're listed at our center, you get two extra points, and then it sort of goes down. If your center is 250 miles from where that donor hospital is, you get $1/250^{\text{th}}$ point, and a point roughly is equal to a year of waiting time.

Then if nobody within that 20-50 nautical miles is interested in the kidney for their patients, it goes out to the national list. And then there's a bit of proximity there too. From 250 and you get some, but it goes down over the miles. What that means is where your center is, and the short answer is, I think it can be beneficial to be listed at more than one center, especially if they're sort of circle, if you will of 250 miles from within it is you know, encompasses some decent sized metropolitan areas.

This is one example of a center in Minnesota. Their circle extends way up into Canada even, but we don't usually get organs from Canada. Lot of North Dakota and South Dakota. There's another center in Minnesota that's about 75 miles south of this one, and that's represented by this red dot. And that center circle ends up getting down into Milwaukee in Chicago quite a bit. And so, there is potentially some advantage to being listed in more than one center. It's again, it's complicated. It used to be that you wouldn't want to be listed at center A and center B 75 miles away, there wouldn't be any advantage. But there might be advantages in certain circumstances where you would want to be, even though they don't seem that far away as a crow flies.

Living donors briefly. One thing that often asked is, you know, how do I find a donor? Well, that's a great question. But donors, we're not allowed to find donors for our recipients. That's frowned upon by UNOS. And by the Center for Medicare and Medicaid Services. So generally, the donor will contact us after they've expressed a wish to donate. And then we have them undergo a very comprehensive evaluation similar in a lot of ways to the recipient evaluation. Some tests are exactly the same, and some tests are a little bit different. And then we would decide if we think they're an appropriate candidate to donate, and then it's up to them whether or not they ultimately going to donate.

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Generally, you have to be in decent health, and nobody's probably in perfect health. But in generally good health. There are some centers that will accept donors with mild high blood pressure or hypertension. And by mild meaning, it's very well controlled on like one medication and not a huge dose of that medication. You may have read historically, for the most part about blood group incompatible transplants or transplants with a positive crossmatch at certain centers. That's not done very much anymore. And that's because of this concept of kidney paired donation.

And the simplest way to explain kidney paired donation is if you have a recipient on the right-hand side here, number one, whose blood group A and then there are potential donors blood group B, that typically doesn't work very well. And then you have another pair where the potential recipient is blood group B, and the potential donors blood group A, which also doesn't work very well. Generally, you have the donor donate to the compatible recipient, and even though they're not related to that person, or even came to the center with the transplant center with that person. But this really helped increase transplantation for a lot of people. Even the number of centers that were doing these transplants across blood group barriers or barriers across the tissue type antibody barriers, that was a pretty small number of centers where this sort of thing can apply at any center. And many, many centers in the United States participate in this.

And these changes mathematically can get quite long. You know, you read in the newspaper about chains of 16 kidney transplants, that sort of thing, separated by days or weeks, and then certainly separated geographically. And so, the kidneys tend to fly around a lot. And generally, it works very well. So, this has been a very nice innovation in kidney transplant and may expand to liver transplants in the not-too-distant future for living donor livers.

How do you find a living donor? I don't have an exact answer for this, because I've never had to look for a living donor. And I imagine it is a very, very nerve wracking and hard thing to do. People handle it differently, I think. And some people are very vocal about their story and what they need. Some are very private and don't want others to know about their health conditions.

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And that's an individual decision and preference, and that should be respected. But I think the long and short of it is you don't really ask anybody for a kidney or most of our candidates don't. I think the more people that hear your story, the more people that are likely to volunteer, and many would, you know, even if you keep saying no, they're going to say I really want to do this. And it's a huge deal. And it's one of the greatest things people will ever do in their lives, I think. But I would imagine it's very, very nerve wracking to go through this, but I've not lived through it. So, I can't, I don't have the exact answer.

But in general, the more people that know, billboards used to be the thing. Now there are other avenues, Instagram, Facebook, other websites that people create, and, you know, propagate their story. And the more people that know your story, I think the better. So that's the long and short. If you're uncomfortable about telling your own story, I think family members or recruiters, if you will, or our champions, they're really good at getting your story out there they can, as long as you let them, they will. They will be very good about advertising your story if you're comfortable with that. Social media is a good tool, I think, sometimes it will overwhelm living donor coordinators because they'll get 200 inquiries from about a certain individual, but that's pretty uncommon. So, I would still favor using it.

The transplant itself in the next few minutes. We don't always remove your own kidneys. These are your old polycystic kidneys up higher; we work from the front, we make incisions lower down in the abdomen. And so, the kidneys into the blood vessels that go to the leg. This is what a freshly transplanted kidney looks like in the operating room. They all pretty much look the same. And this is what a normal kidney looks like. This isn't obviously not a polycystic kidney.

Surgery of any type has risks. There are infections that can happen. Transplant patients are a little more at risk for certain types of infection. And most of these are any, you know, complications related to any surgery and being in the hospital. Things that aren't you know, if you had your colon removed, things that don't apply to that are things like rejection of the new

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organ, and then just delayed kidney function or delayed graft function we talked about needing some dialysis after. There can be leakage of urine or other issues with fluid after the transplant but most of those can be dealt with in the time, you're spending near your transplant center recovering.

Very, very common issue for patients with PKD is what to do about my old kidneys. General rule of thumb if they're not bothering you, many times we just leave them alone. But there are reasons we will remove them, or the patients would like them removed. And that's oftentimes pain in this by that I don't mean the occasional twinge. But I mean people with life limiting or barely severe pain, some people even on narcotics then you know really being full that was really large kidneys and not being able to eat very well. There are patients as you may know the recurring infections of the cysts or bleeding from the cysts. Rarely there's a case where there's not enough room for the new kidney, or dissection to put in the new kidney that's pretty uncommon but can happen and then occasionally there's a suspicious cyst or more commonly a mass on a polycystic kidney and that can be very hard to tell, there we might be worried might be a cancer, and then they should be removed.

This is a CAT scan of a patient with polycystic kidney and a little bit of liver cystic disease as well. The old kidneys are highlighted and surrounded by yellow. And then the new kidney is in green outline, they're lower down in the pelvis. These were not are not massive PKD kidneys by any means. This is a different example of a patient prior to transplant and these kidneys were really quite big. And so, these actually were probably in the category where they needed to come out before new one went in.

Depends on where you go, how that center will address your kidneys, our current approach, at least here in Rochester, and at Mayo Clinic, Arizona is to remove them at the time of the transplant. And so, you have one operation. It's a longer operation, and it takes a little longer to recover from but usually just one and then you get the transplant after those kidneys are out. But some centers prefer to remove them afterwards. That used to be our approach, we would remove it, you know, three to four months after a transplant. Some are

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pretty dead set on removing in before, there's no right answer. It's more just practice preference. But at least the way we're doing it, we think is worked out nicely because patients just have one surgery. But certainly, even if you have a transplant tomorrow and your kidneys are not bothering you now, a year or two down the road or five years they can be removed if symptoms do develop.

This is an example of one of my partners, Dr. Miguel Prado who has really been a pioneer in removing these very large kidneys. And this is an example of one of the kidneys he removed. And this is done through a minimally invasive technique where you have about a seven- or eight-centimeter incision, and then laparoscopic instruments are used. It's pretty slick the way he does it. And this is the same way we would do it at the time of the transplant.

So, in summary, and then we'll have time for some questions. And I see quite a few coming through on the chat and we'll get to those in just a second. You know, I do think it's important to go to a center that has and there are quite a few across the country that have experience with transplants, and certainly with PKD as well. You know, we recommend you're in as good a shape as you can be before and after the transplant. Ideally, you're able to find a living donor, but it's not anybody's fault if you don't. It's a complicated process. And its many people are able to find quite a few people that are interested. But they're just not a candidate for some reason. That doesn't mean they can't help in other ways be a caregiver. So, it's nobody's fault if you don't have a living donor. But and this is a bit like preaching to the choir with this group, but I think the best patient is an informed patient and one that can advocate for themselves.

So that's what I have. My contact information is here, it's probably in the profile on the PKD site as well. But certainly, feel free to call or reach out by email anytime you like. We're happy to answer your questions. This is put in by the PKD colleagues at the foundation. And this is just to remind you that there is a registry. Occasionally people that have their native kidneys taken out these kidneys can be sent to research facilities that use those kidneys, for

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example. And this is it. But that doesn't mean you can't - you can be in the registry without that this is just sort of to see how people do that with PKD and after transplant.

So, I'll go up to the chat. And I'll stop sharing my screen here. And so, I can look at you and we'll go to the chat and answer a few questions. The first, I'm just going to take them in order. The first question is, essentially, is it possible to have a third transplant? And it is. The second part of that question is how much difficult is it? From a surgery standpoint, it's not a lot more difficult. It probably adds a bit of difficulty that it's a surgery but it honestly until you end up with the fourth or fifth or that kind of numbers of transplants is not a lot different. Usually, there's plenty of space. You just put it in a different spot on the blood vessels. I think one thing that is maybe more difficult is oftentimes folks are older by the time they end up with a third transplant. And so, the way they recover may be a little different than what they remember from the first couple. But certainly, basically, third and fourth and even fifth are possible.

Next question is when the call comes with the offer of a kidney from a deceased donor, what are the questions one should ask? I think that's a good question. I think you don't need, you shouldn't need to ask a lot of questions, honestly. The center's not probably going to tell you where that donor is, how old they are. It's fairly generic. And that's mostly in the interest of protecting the donor's family, because of newspapers and news and social media, and it's sometimes not as hard as you think, to put things together, who that who it might have been. So, the main thing is to keep the anonymity of the donor, I think, hopefully, you're going to be listed at a center that they wouldn't call you unless they thought that kidney was appropriate. And I can't say that's the case everywhere. But I think that's an important thing. We typically won't call you unless we think the kidney is appropriate. And it's, you know, not, I don't know that it's, you know, that someone who hasn't, you know, been trained in the area, it would be fair to ask them if they think they want this kidney. So, we generally would not or at least our practice, we wouldn't call you unless we thought it was an appropriate organ for you.

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Is the kidney transplant surgery more specialized or different for PKD patients compared to other medical reasons for kidney failure? The surgery itself generally is not much different. It's probably in some ways, a bit more straightforward because people with PKD don't tend to have as much cardiovascular disease. So, their arteries that we're working with tend to be a little bit nicer to work with not as much hardening of the arteries. And then so but unless we're going to take the kidneys out the same day, and that obviously adds, you know, a few hours to the operation. But it generally will not be a lot more difficult.

And then are the transplant outcomes stats same for PKD patients and other kidney failure reasons? Probably, we don't have them specifically for PKD from a national standpoint, but my suspicion is they will be better because that graph, that failure also includes patients that died with a functioning kidney. And so that can be a big reason. And in general, patients with PKD don't have you know, the other comorbid conditions like severe diabetes, or heart disease or that sort of thing. Again, the kidneys are sick because they have a genetic problem, and they're not sick because the patient around them sick.

So, the next question is, are prospective transplant patients at a disadvantage who have Medi-cal slash Medicaid insurance? Typically, not. I don't know Medi-cal specifically because I've never worked in California. But Medicaid is you know, that generally is restricted as far as where you might be listed, that would be one difference perhaps than if you came with Blue Cross Blue Shield or a private insurance or even Medicare. Medicaid is a state-based system. And so oftentimes, they only will have reciprocal relations, meaning that with states that kind of touched them, and that's not always the case, for example, Iowa Medicaid doesn't cover a kidney transplant in Minnesota. But Wisconsin Medicaid does. So, that'll depend more on the state's rules about their Medicaid but from a, you know, kidney allocation system or your eligibility for a transplant at a center that is covered by that Medicaid, I don't think you'd be disadvantaged.

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Is there a BMI that is too low for transplant? I don't think BMI itself. I think if a say somebody a BMI has of 17 are something really low, I think are 18. I think that would depend on if that's because they're just really small, which happens there are small people. Or if it's due to poor nutritional status, that might be the only time you want that improved before you would do a transplant, I think. But there's no it's not something we encounter commonly, to be honest.

The next one is what valve issues would prevent or delay approval? I assume this is referring to heart valves because the next question is MVP. So mitral valve prolapses, that shouldn't it would really be significant valvular disease. Sometimes people need their aortic valve, or their mitral valve replaced prior to transplant because there's so much leakage around the valve or it's so narrow, but that can generally be dealt with.

Can they deny a spouse for donation if we have young kids? Not outright. I don't think most centers wouldn't. But some might if they think if the psychosocial evaluation of a donor evaluation means that they think it's too much burden. But that's, I think, a very subjective thing. And I wouldn't say that would be a common reason for denial. But I can't promise it hasn't been used. A few more questions in the last three or four minutes.

Do the native kidneys ever continue to grow and cause the impact of the transplant? It is generally not they, even if they grow, they're unlikely to affect the transplant kidney. But when we've studied this, they tend to they don't get a lot smaller, but they don't tend to get a lot bigger. And they rarely would cause any problems on the new kidney.

How many days can pass between harvesting and transplanting of a kidney? How is perfusion maintained? So, there is no perfusion this is these kidneys are on ice, there are some pumps that are used. But that's just cycling a preservation solution through the kidney not oxygenated, or blood. Then generally we'd like to have the kidney within to the recipient within 24 hours is a good rule of thumb, but you can push that out to 36 hours, especially if you're using some of these preservation pumps, but 24 to 36 hours.

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Next question is I'm a woman and I have three kids, a friend told me that my husband wouldn't be able to donate to me because he's a man and hasn't birth any kid. Is this true? No, that's not true. There is possible that because of the some we met, we talked about these tissue type antibodies a little bit. People that have had pregnancies or prior transplants or a lot of blood transfusions can develop antibodies against certain tissue types. So, but the way to, but without testing your husband's blood, I wouldn't say they can't donate directly to you.

The map you showed of centers in the 250 nautical miles where that's from? That's from the UNOS website is that map, they and you can probably search, UNOS kidney allocation scheme or something like that you should get to those maps.

Then there's this, how do you find a good transplant center? That's a fantastic question. The follow-up to that is does it matter if they have a PKD clinic? I think it does. I think it's or whether they have a formal PKD clinic I don't even not sure what that is. Although I saw the slides going forward. I think they should have experience with polycystic kidney disease. There may be, you know, a nephrologist at a very small center that sees a lot of patients with PKD. It's not common. I think it's helpful if that center has experience with PKD, partly because some of the liver issues, the brain aneurysms that sort of thing is important. And if you look at most outcome data in any kind of healthcare volume does tend to relate to outcome. I'm not saying that there aren't some good smaller transplant centers in the country. But if you look at heart surgery, if you look at pancreas cancer surgery, if you look at any kind of, if you look at CHF heart failure, those sorts of things volume tends to equate with outcome. So, I would pick a larger center but that's me.

And I'm happy to go a little bit longer if you guys into your stretch break if for those of you that are interested in staying on answer a few more questions. That was the five-minute warning five minutes ago then there's then there is a survey too. There's a good question, can PKD develop in the new kidney? And the answer is generally no because the PKD is the gene in your own kidneys or in the recipient's kidneys and the new kidney doesn't have that

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gene. So typically, now occasionally a kidney will have a cyst on it or develop a transplanted kidney you'll have a cyst but not polycystic kidney disease.

And some and then see Joe's got a couple of things and then can someone with the duplicated system donate and what if the donor has kidney stones? I assumed by duplicate, okay, now I'm just going to assume that the ureter or the urine system that drains the urine from the kidney is occasionally duplicated, and that can be used donors with that. Sometimes it's both sides, sometimes it's just one side, but to your kidneys can be used just fine. And then the other part of that question is, what if the donor has had kidney stones? I think that totally depends.

So, when we see people with kidney stones, whether they have passed a stone historically, or if they, and generally that's documented on some sort of CAT scans, usually the way that's been done, or if sometimes we find people with stones that they didn't know they have when we're doing the donors when we do a CAT scan to look at their anatomy and their kidneys. Some donors with kidney stones can develop or can go on to donate, excuse me if they're not what we call active stone formers, and they have a relatively small meaning one or two stones probably only in one kidney, and we would typically remove that kidney. And they generally don't cause problems in the recipients. Rarely they can but the way you tell if somebody's a stone former or currently is this is you do, you measure the level of different elements like calcium and phosphorus and other chemicals in the urine, usually with a 24-hour collection. And if there's a lot of those, it means they're more likely to form stones.

What happens with the adrenal glands? The adrenal glands in the donor are not affected. They're separate from the kidney. And even though the textbook I learned anatomy from it showed it like a hat sitting right on top of the kidney, and that's it's actually a little bit separate and there's a nice plane and so the adrenal glands will stay in the kidney donor and on the in the living donor keeps their adrenal glands. In when we take out big polycystic kidneys, we are usually able to preserve the adrenal glands too. Rarely one has to come out. The good news is you only need one. So, it's kind of like kidneys.

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When do you think scaffold grown kidneys are humanized kidneys will be available? This is an excellent question. Related to that is sort of the pig kidneys that you might have read about. I think probably my guess and I'm not, I'm not a researcher involved in scaffolding and growing kidneys that way, I think that's probably 15 to 20 years out. But that's a guess I hope it's a lot faster. But I'm guessing something like the complexity of these organs is such that it to reproduce in a box or a dish, or however you want to do it is I hope it's faster than that. But I'm and the pig kidneys are probably 10 to 15 years out, I would guess.

Joe: I want to jump in and just say we've got, I think time for one more question, and then we'll have to have to wrap up here. So, we're going to take some stuff, get into the next session. But thank you all, and thanks for sticking around Dr. Dean.

Dr. Dean: Oh, happy to. The question about the large PKD kidneys? I've not seen that. But it's probably possible on the nerves. And then the last one would be what is the usual GFR for needing a transplant I was told that body chemistry was more important for PKD patients than GFR? I think that what that question gets at is that oftentimes people with polycystic disease tolerate a lower GFR than others, again, because they're typically not as sick overall. And so, you know, I don't think there is a number, you know, most of the people we transplant are probably 12 to 15 in general, but we have some people with PKD that ride it out at 7,8,9. Again, because they're generally pretty healthy around it so.

Well, thanks so much, for those are excellent questions. We actually covered most of the things that I would answer in clinics so that was really well done among the groups so.

Joe: Thank you so much for your time, Dr. Dean. And thank you everyone else for joining.

Dr. Dean: My pleasure.

Joe: Please be sure to fill out the survey before you take off. You can find it in the chat thread there and we will see you at other sessions. Thanks so much.

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Dr. Dean: You guys have a great weekend.

[Audio Ends] [00:50:45]