

Understanding Nephrectomy

Dr. Watnick: So, we're going to be talking about nephrectomy surgery, understanding the risks and benefits.

Gillian: Just one more moment. Before you begin, I just want to share with everyone, if everyone can just, please make sure to mute yourself, so that the only people on are Dr. Scalea, Dr. Watnick and I will also be on. My name is Gillian Karnik. I am one of the volunteer coordinators for the PKD foundation. But if everyone else can mute themselves, we would really appreciate that. Thank you, everyone. Okay, Doctor, back to you.

Dr. Watnick: So, this was just the activity disclaimer, which I think you guys want me to show. So, take 10 seconds to read it. The next slide is a disclosure, I don't think that either myself or Dr. Scalea have any conflicts of interest to disclose. And so, I'm going to start out by sharing something that I think you guys already know which is that the symptoms of polycystic kidney disease are directly related to kidney size. And so, what I'm showing you here is a graphic of the PKD kidney over time, and you can see that over time cysts develop, the kidneys get very large. And that leads to the signs and symptoms which you're familiar with including cysts rupture, hematuria or blood in the urine, cyst infections, kidney stones, other types of urinary tract infections and then most importantly, pain, abdominal distension from the kidneys getting quite large and taking up most of the abdomen.

So, as the kidneys begin to stop working, the issue of if you're going to have a kidney transplant, should your kidneys be left in or not usually comes up. And to the right here you can see a picture of an MRI and you can see that these how big the kidneys get and there's not a lot of room left. So typically, we do not routinely perform native nephrectomies. But there are kind of agreed-upon indications to have your kidneys removed at the time of transplant. And those include insufficient room for the new kidney to go in, recurrent bleeding, recurrent cyst or urinary infections and the reason that's important is because once you're immunosuppressed, the risk of infection can go up. Symptomatic and recurrent kidney stones, very severe pain that's unmanageable or early satiety, meaning that you can't eat as much as you'd like or suspected malignancy or cancer in the kidneys.

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So, one thing to know is that several studies looking at this in a retrospective way have found that there is no difference in graft kidney allograft or patient survival between those who have a native nephrectomy, or their kidneys removed at the time of transplant versus those who don't. So, that in itself won't affect the health of the kidney transplant. And so, what usually is asked, as you're weighing the risks and benefits of whether to take out the native kidneys or to leave them in is what will happen to the native kidneys after transplant. So, do they get bigger? Do they stay the same? Or do they shrink? And so, it turns out that at least two studies looking at this in a retrospective way, have reported that the volume of the native kidneys actually tend to decrease after you have a kidney transplant.

And here I'm just showing you data from one of those studies by Jung et al from the Mayo Clinic where they looked back at their patients that had been transplanted. And so, it's not a prospective study. It's a retrospective study, but they were in their database able to identify 78 patients who had imaging before and after transplant but not at any fixed time. And they were on a variety of immunosuppressive regimens. And what they found is that, in fact, the kidneys decrease in size and most of the decrease occurs within the first year after you have a kidney transplant.

So, on their study, the kidneys decreased in size by about 20% after about a year. And then you can see the rate goes down. A total of 38% at about six years. And so, and then to the right here, you can see a picture of these kidneys, just showing graphically how large the kidneys were pre-transplant a little bit smaller at six months and then even smaller at three years after transplant.

So, there's another study reporting something similar. So, the one caveat, I guess, with these studies is that they're retrospective. So, there are a lot of variables that you can't really control for. But nonetheless, this seems to be generally the case. This is just showing each of these lines represents one transplanted person. And this line is looking at the total kidney volume in relation to the time from the renal transplant. So, you know, there's a lot of patients here, but you can see that, in general, the trajectory is for the kidneys

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to get a little bit smaller. So, that that can factor into your decision as to whether to have a Nephrectomy and or not.

So, the next question that always comes up, is what about the timing of native nephrectomy? So, you could do it before the transplant, you could do it at the time of the transplant or you can do it after the transplant. And these are kind of hard studies to do, again, because they're retrospective and uncontrolled. But just thinking about it, there are advantages and disadvantages to each one of these options.

So, what about getting the nephrectomy before the transplant? So of course, the one main potential advantage is that there's less risk to the transplanted kidney because it's not there yet. However, there's a big disadvantage, which is that if you are not on dialysis at that time and you're considering a pre-emptive transplant, you're going to need a period of dialysis before you can get a transplant and that is kind of difficult for a lot of people. And then there's loss of any residual function if you are on dialysis.

And so, what about the opposite native nephrectomy after transplant? The advantage to that is that there is no need for dialysis because the transplanted kidney is already there. But the big potential disadvantage is that if there's any hemodynamic or blood pressure instability during the surgery or other complications, there would be potential for injury to the transplanted kidney. And so, these are really kind of difficult studies to do.

And I'm just looking at one. One study that I found from the Mayo Clinic again, comparing people who had nephrectomy before transplant with 79 that had it after transplant. And what they found is that the incidence of complications was higher in the people who had had a pre-transplant nephrectomy. So, the complication rate was lower if you had your nephrectomy after transplant. So, that was 26.6% versus 48%. And a lot of those complications had to do with time in the hospital and also with needing a blood transfusion. So, if you need a lot of blood transfusions pre-transplant, that can be bad because you can become sensitized. So again, this study is limited, because it's all retrospective and the timing of these things was not

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the same. But there have been, there's at least one other series reporting something similar.

So, the next option is the timing with respect to the timing of native nephrectomy is to have it done at the time of transplant. And this has a lot of advantages. First is that it's just one surgical procedure. If you're having it before or after your transplant, you obviously need to have two procedures. If you're having a pre-emptive kidney transplant, there is no need for dialysis. And then when this has been surveyed and Dr. Scalea was involved in this, patient satisfaction is a huge factor. People really, really prefer this to the other options. As with anything, there are some potential disadvantages, including unanticipated surgical complications, which can always happen. It's a longer operative time compared with just having a kidney transplant and a longer hospital stay. There's an increased need for blood transfusions. And of course, when you take out the kidneys, there's a loss of residual function. But as I looked over all of this literature and thought about it, I think, in summary, different transplant centers have different approaches. And it really does in the end, depend on the experience of the surgeon.

Additional questions that people have is whether to consider a single nephrectomy versus a double nephrectomy. My feeling about that is that all of the potentials for complications in terms of bleeding and pain may still remain if you leave one kidney and but of course, then you also may still have some residual kidney function. People sometimes ask if native nephrectomy can be done laparoscopically. I'll let Dr. Scalea comment on this. And of course, this is a field that's like improving all the time. So technically, it could be more difficult, and you could also have the potential to convert to an open nephrectomy, but certainly, as people gain more experience with this, it's going to get better.

So, I just put this in here as a summary, because I don't know if these slides are going to be made available. But I just summarized all of what I just told you in this table. I'm not going to go through it again. But if the slides are shared, you would have that. And so, I'm going to turn it over to Dr. Scalea with that.

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Dr. Scalea: Thank you for the opportunity, and to the entire group for the opportunity to share some experience. And I'm going to first acknowledge the fact that what a lucky group, you know, Dr. Watnick, is world-renowned for her experience in this space. And she's delivered some really great points and what a wonderful resource, both presentation and then in slides afterwards.

This is a series of, you know, facing some difficult decisions here and big operations, right, removing kidneys, and then certainly doing a transplant. And these are very common questions in terms of our surgical approach. In many ways, one is, you know, we take the timing, as was just beautifully described and I can touch on some more details there from a surgical standpoint. And then separately, how do we do it? And then how does this affect the patient? I'd like to first briefly discuss timing because that is probably Terry, the most common question regarding this operation you seem to agree.

Just remember there are if you don't do the operations together if you don't do a nephrectomy and a transplant, at the same time, you're getting two operations. And so frequently, we talk about complications, but we're talking about complications of the nephrectomy, or the transplant were not frequently described describing the complications of both of one operation the simultaneous nephrectomy and transplant when we compare both operations, the nephrectomy and a subsequent transplant. So, although the complication rate as described may appear higher, the blood loss rate may appear higher. Remember that if you're not getting both operations done at the same time, you have to undergo two operations and cumulatively, you're exposing yourself or the patient is exposed to a potentially higher rate of complication or a different series of complications. And so that's at least worth knowing.

And then, in terms of preference, you heard Dr. Watnick mention that most patients enjoy having both operations done at the same time. That is the nephrectomy and the transplant, and why, you know, this recovery, there's pain, there's inpatient hospital stay, and it's certainly nicer to have both done at the same time.

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This slide does address some of the complication rates and clinical parameters that we see perioperatively with the living donor kidney transplant alone versus that with a bilateral native nephrectomy, and we see that the operative time is higher. And that's true. It's true because we're doing a little bit more work. And we're exposing the patient to a little bit more blood loss. But remember, again, that if the kidneys are coming out, at some point, there's going to be an operative time associated with that, whether or not it's in one operation, or if it's in a second operation, there's a little bit more blood loss in a bilateral native nephrectomy. That's true. But again, you know, two operations first one, you know, we're not really comparing apples to apples here.

The mean amount of time in the hospital is longer if you get a nephrectomy versus if you just get a transplant. And why might that be? Well, when we remove the kidneys, these are big, they're really big, and they are frequently touching the intestines and other organs within the abdominal cavity and those organs are typically just fine and don't get injured. But as a result of that inflammation slows down your intestinal motility. Motility takes another day or two to start eating and drinking and rehab will just take a little bit longer to heal from that operation. And so, I think, that largely covers the kind of the primary concerns that we typically hear. Re-admission rate maybe a little bit higher in the group that receives a kidney transplant and a bilateral native nephrectomy.

But again, you know, it's a slightly larger operation with a little bit more inflammation. And I sort of look at it, as Terry likely does as sort of an investment. This is to get you all the way through the challenges of renal failure as a result of polycystic kidney disease and get you all the way on the other side of dialysis, which results from the removal of kidneys after which of course, you are not making any additional urine. And so that's important, let's go to the next slide. And so, there are a series of different potential approaches to management. I think this is Terry's slide, I'm happy to present it or Terry, if you'd like to go ahead and present it, that'd be fine.

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Dr. Watnick: Okay. I think I took this from a review paper. And I think this is the algorithm that maybe, most of us follow which is as the patient is approaching the need for renal replacement it's usually the nephrologist and the surgeon together who are assessing, are there any symptoms from the native kidneys. Is there recurrent bleeding? Have we had problems with recurrent and resistant infections? Is there really pain that's impacting quality of life? And is there room for the transplanted kidney to be put in? If the answer's no, then we kind of just go ahead with the transplant. But if the answer to these is yes, and if the surgeon and the nephrologist consultant feel that the patient would benefit, we'd go ahead.

Is there a need for residual diuresis? So, this is I guess, you decide that most of the time, I'd say the answer is probably not, especially if the patient is going to approach the need for end-stage kidney disease and the kidneys aren't working that well. So, if you decide that you're going to go ahead usually we would opt for taking out both kidneys. Simultaneously with the transplant assuming that the surgeon feels comfortable. I usually haven't been in a situation where I've opted for a unilateral nephrectomy. Because normally, when you're having bleeding or infections or a lot of pain, leaving one kidney isn't really going to solve that at all. So, Joe, I think that is the last slide that I have.

Dr. Scalea: I'm going to just chime in on the unilateral kidney. Yeah, there are a couple of surgical and technical things guys that I think are worth discussing in the context of one kidney versus two. There are some anatomic challenges to certain kidneys. And if you're one of those unfortunate polycystic kidney patients to have multiple cysts ruptures, you know, one kidney may be very adherent to critical structures that may be blood vessels or otherwise. And when the surgeons get, typically surgeons can see most of that on CT scans in advance. But there are times when you get in to do those operations and you take one kidney out and you say, oh, my gosh, that was a little bit more complex than we anticipated, we're just going to stop at one out of concern for the sort of the patient's everything from hemodynamics to recovery and you may come back to sort of, in quotes, fight another day, and remove it at a different time. And that's perfectly fine. It does require a second operation.

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That's true, but it's sometimes in the best interest of the patient, that would be about it, for me.

I think if you're committing to taking out the kidneys, they have inherent risks. I get particularly concerned about infections. So, if patients have had infections in the past with their ruptured polycystic kidneys or infected cysts, infection is one thing when you don't have immunosuppression on board. And for those who are not aware, immunosuppression is a series of drugs that we use to ensure that your kidney doesn't have rejection. When you're on immunosuppression, it also inhibits your body's ability to fight infection. And so, if we've got those kidneys in there, and they have a history of infections in the past, even if they're small that can be very difficult for us to treat after a transplant. And so, if we have the opportunity to remove them and there's any indication that they should come out, we generally try to opt for removal as long as it is anatomically safe. But I think with that, we could open it up to questions to the group.

Dr. Watnick: Before we open it up to the group, if that's okay, I just going to plug a couple of studies that are ongoing. So, one, I just want to if anyone has polycystic liver disease, that is not due to either PKD 1 or PKD 2, Dr. Whitney Besse at Yale is looking to identify new genes relevant to cyst formation and to study how these new genes cause cysts in order to design therapies. So over here are the eligibility criteria and I'm sure you can participate. That will be in the slide. And then a second study undergoing that I'm working on which is to look at the genetics of brain aneurysms in PKD. We want to identify those genetic defects aside from the primary PKD mutation associated with aneurysm in ADPKD and again, we are looking to collect blood samples for this both of these studies can be done remotely, you don't have to come to either New Haven or Baltimore. It's all done by phone and by mail. So, with that, I'm going to turn it over to questions and answers.

Gillian: Perfect. Thank you so much for that, too. I think it's always great for people to see what research opportunities are out there. I know I have been volunteering with the PKD foundation for coming up on 20 years this February. Dr. Watnick, I just want to say I know you have been a wealth of

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information throughout those years. So, I really appreciate that you just continue to help us learn more about this disease. And Dr. Scalea, thank you so much for what you are joining in with the conversation because for patients like myself and many of the folks that are on here, it's just terrific that we can interact and get this information and make the best decisions for us and our families moving forward. So, we do have a few questions here in the chat.

And I will start with our first one. Our Transplant Center didn't present simultaneous nephrectomy as an option and seem to downplay nephrectomy in general. From talking of other patients, transplant centers have very different views on nephrectomies more common at some centers, rare at others, isn't there a standard of care about nephrectomy?

Dr. Scalea: I can take that if you like I can chime in with some surgical background. And then perhaps a more comprehensive thought from Dr. Watnick. I'm going to try to not be too professorial, I promise. But if I go on, somebody just cut me off. The first transplant was done in 1954 and we didn't scale transplant as an industry really until the 2000s. And I know that's hard to believe. But we didn't really have active immunosuppressive drugs available until 1995. 1995, to say that, again. That was not very long ago. And so, the total number of kidney transplants done every year in the United States is about 25,000 or 26,000. And about 6000 of those are living donors. That's not very many if you think about a population base of 370 million people.

And so, in that time period, there's been an enormous amount written, thought about, discussed lately about the role of transplant in polycystic kidney disease, let alone simultaneous removal and timing. And so, when me summarize all of that, just by saying there are a series of different views. And they are not because we have the lack of interest or standard, but quite literally, there's been an organic growth in the knowledge base around this topic. Separately, the skill set required to remove kidneys safely and then simultaneously perform a transplant and perform what I'm going to just call perioperative care, which includes management of blood pressure, dialysis

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requirements, what we might call delayed graft function, kidney biopsies and imaging, varies to some degree from hospital to hospital.

There are 253 transplant centers in the country, about 50 of those are relatively high volume, you'd almost certainly need to be in one of those centers. And so, to answer the question now, directly with the background, is there variability? Yes. Is it reasonable? Yes. Is the variability in both surgical technique and care? For sure. And I think that your doctors are always going to be interested in what is best for you that is true. And they will do that within the scope of their resources at their own facility. Now, part of the reason that conversations like today's are so important, is because it's important for folks like yourselves to understand that these options do exist. And so, if you really are having a series of symptoms, and you don't feel like the solution presented is the best for you, it may be worthwhile to have discussions outside your current group of physicians or at least address with them how it might look. Final comment 30 seconds, and I'll be done.

Downplaying nephrectomy does occur. That is not because someone can't analyze the data the same as Dr. Watnick and I can, but with limited experience, you may say I just don't see the value in it, because you've quite literally never seen the value in it. Again, the number of people for whom this is done is quite low. And so, I don't think that those folks should be faulted. But I do think on an individual basis, there's nothing wrong with a second opinion at a center that may do those surgeries or an ongoing discussion with your current surgeons about you know, it's kind of if then and, and why we're making the decisions that we are, is would be warranted. So, there is a lot of variability. And it's for a series of reasons, and I hope I've done a reasonable job trying to articulate those to you.

Gillian: Yes, I think you did. And I think just from many patient groups, PKD patient groups on Facebook, you see that all the time, people say, my surgeon says we're just going to do a single nephrectomy or were, you know, nope, we did a double. So, there is a lot of variability based on where you go and finding maybe some of those high-volume centers. We can talk about how to locate

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some of those if there are ones in your area if you need to get a second opinion.

Dr. Scalea: Let me say that. Not every car, I make a lot of car analogies, but not every car has to be a Ferrari. They all work fine. Okay. So, if you're in a situation, it could be geographic, it could be rural. It could be for any number of reasons it could be just there's some restriction on where you go. Just because you're having an operation where the kidneys are removed either before or after a transplant, it is not the end of the world, it really is fine. You're not the vast majority of the benefit is quite literally the removal of the kidneys, and then the transplant in whichever order. But there are some benefits to sort of each of those, the cadence of each of those and families differ. Some families may have specific requirements that make them feel more comfortable with any of those. And I do think they are, let me just say very clearly, they are all medically indicated. And they are all medically very reasonable, based on an individual's presentation. So that's okay.

Gillian: Okay, thank you very much. That's very helpful. All right. So, this one is from Kristin. I am 50 normal weight and do some yoga, I have a lot of lower back pain. Is it likely related to my PKD kidneys or not likely? My Nephrologist is unsure but said they are not very experienced in this area. So, could that pain be coming from the PKD kidneys?

Dr. Watnick: So, I guess I'll take that one. And I'll just want to say that I haven't seen you, I haven't evaluated you directly. But it is always possible that it's contributing. So sometimes, you know, it sounds like musculoskeletal back pain. But that doesn't mean that there's not a contribution from the kidneys, it may not just be due to one thing. So as your kidneys get bigger, it's been appreciated that posture changes, and you can get like lumbar lordosis. So, it could be an interplay of those factors, not just one or the other would be what I'd say. So, I'm sure like if you maybe you didn't do yoga and you didn't bend in a certain way, maybe your lower back wouldn't hurt. But it doesn't mean that there's not some contribution from having larger kidneys as well. So that's what I would say.

Dr. Scalea: I would defer to the doctor.

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Dr. Watnick: This kind of stuff comes up a lot. And I would just say practically speaking, listen to your body. I mean, if something is really causing you a lot of pain, then I would probably try to not do it.

Gillian: Okay, very helpful. All right. The next one is from Scott, his family history of severe symptoms with native kidneys, such as size, cyst rupture and pain. Is that family history ever a factor in deciding whether or not to conduct a nephrectomy like taking them out proactively?

Dr. Watnick: All right, I'll take that. First of all, I don't know that family, like if you had a relative that had infections and cyst ruptures, those things are related to the size of the kidneys. So, I think family history is contributing very indirectly. And I would more look at the individual patient and assess whether or not they're actually having those symptoms. I mean, if you're because there are some sex-related differences as well and activity-related differences and environmental factors. So, just because a family member had those things, I would not recommend taking out the kidneys just based on that. I would more focus on the particular symptoms that you are having as a patient because you may or may not go down the exact same path. But Joe, I don't know if you want to comment on that, I think.

Dr. Scalea: To be very brief, I would engage Terry Watnick, that's what I would do. So, I think, though that there are lots of reasons to have your kidneys removed, not the least of which it freaks me out to have these kidneys. And I'm nervous about them and my cousin and my brother and such and so forth. And so, what you heard Dr. Watnick describe and her clinical protocol for when we decide to remove them was sort of an agreed-upon series of indications. A person's reaction to their kidney is important to me as a physician, and if these things are keeping you on edge, and it is like, you know, let me give you a very clear example. And then I think it'll explain everything, patients come in, and they're pretty clear, I need to have these things out, they've got to come out, right. And that is a different patient than one where they don't bring it up at all. And you say, do we need to have your kidneys removed? And they would say, why? You say, well, are you having infections, pain, and such and so forth, hematuria? And they say no and removing kidneys as an

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option if those things occur, and they say, well, I'm not having them. And then that's a very different patient, you see.

And so, I think, in the context of what was described, I think I would see the patient I would evaluate them I would discuss with Dr. Watnick we would understand the size risk and go through that series of questions. And most likely patients that are in that group, tend to say I just don't want to go through that I want them removed. And we tend to agree and move on with nephrectomy. That's the grey area.

Gillian: Yeah, so it's really a patient, patient by patient decision.

Dr. Watnick: Yeah. I want to echo that it's really individualized. And you have to listen to the people who as Dr. Scalea does, listen to the people who are coming to see you and take their concerns seriously and then also make an assessment of what's going on clinically.

Gillian: Okay, we have a question from Kathy, about how many kidneys that you have removed, were able to be donated for research. Is that common with PKD kidneys, you know, after removal, having them donated?

Dr. Scalea: I mean, I can ask, but I'm going to invoke Dr. Watnick so that you could be at the center like the University of Maryland, where as soon as you remove and turn around Dr. Watnick steals it from you and takes it to the lab. And so, it'd be at a center that sort of pulling in the direction of research, I'm being silly, but I'm sort of only being silly. And then there are centers where there's not a lot of research on site going on, that requires pretty substantial infrastructure, for those kidneys to go to research, they're always helpful. I will tell you that the research studies are usually quiet, you know, by overwhelming a research protocol with additional kidneys does not necessarily imply a better outcome for the research study.

So, just if they had 10,000 kidneys instead of 40 kidneys, based on what they're doing, it may not actually be more helpful. So, just the will to be involved in research, number one. Reading the research and being sort of involved in the community, contributes just as much potentially as actually donating your kidneys. And so whatever research protocols exist I would

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encourage you to participate if you're interested. But if you're not, don't feel like you're somehow committing, you know, set anybody else back.

Dr. Watnick: Yeah, I'll just come in on our protocol when patients at the University of Maryland are going to have their PKD kidneys removed, we do ask them if they're willing to donate their kidneys. And we actually go into the outside in the O R and get the kidneys right away. And the big advantage of that is that they don't sit around for a very long time. So, we bring them over to pathology ourselves than we take them in the lab and we're actually using that as material to give to the entire PKD research community who may not have access to it. It's not just for us. So, we're one of the PKD centers, the NIH-funded PKD centers, and our mission is to actually take advantage of those protocols we have at Maryland to not use everything for ourselves but to really share broadly with the community throughout the country. So yeah, and the fact that we get the tissue and it's just right been taken out is really a huge advantage.

Gillian: Yeah, that's terrific. Okay, so I'm just trying to see if I can put some of these together. This is a question about minimally invasive nephrectomies. Although the surgery would last longer, isn't it ultimately best for patients to have a minimally invasive nephrectomy, instead of the hip-to-hip surgery?

Dr. Scalea: It depends. Just remember, I'm trying to be short with my words, sort of what goes in must come out. I mean, at the end of the day, these kidneys are huge. And so minimally invasive surgery has just simply has its anatomic limits. I mean, the kidneys need to be removed. So, there are very, very few centers that have tried this topically. It has been tried at many centers laparoscopically or minimally invasively and abandoned. Because it is so time-consuming, that it actually puts the patient at more risk in the O R to do it laparoscopically. The notion that you would be in the O R for 10 to 15 hours as an example, has its own risks that supersede potentially the risks of a larger incision.

The incision is typically up and down. It is not typically side to side. I just want to pick up on that nuance of the questioning. And there's an incision, it's the same incision through which we then do the kidney if we do it

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simultaneously. And so, I'll stop my comments there. But there are some centers that do it. Some centers that don't There are let me just say there are almost no centers that do it minimally invasively I mean, that is a very heavy lift.

Gillian: Yeah. And we had another person that asked about that as well. So, I'm combining those two together. Dwight had asked and I know this is something that people have often wondered what percent of removed kidneys have undetected cancer that maybe would have been found after but maybe had been masked by the sheer amount of cysts with a polycystic kidney.

Dr. Watnick: Do you want me to take that or comment on that, Joe?

Dr. Scalea: Yeah, sure.

Dr. Watnick: Yeah, it's actually not a very large percentage. Obviously, when the pathologist gets the kidney, they are not looking through every single cyst. So, I'd say it's a small percentage, but that's part of the reason why we focus on recurrent gross hematuria or having blood in your urine repeatedly. Because that can be a sign of malignancy. So, that's why we are so keen on that. If someone's having repeated episodes of bleeding, it's a possibility. So that's why we would sort of want to take those kidneys out. But when they actually look pathologically, I've seen some studies, it's a relatively small percent, but what we don't know is, since they're obviously not looking through every single cyst, whether there would be some foresight that are missed.

Dr. Scalea: The number is, anecdotally the number as just described is very, very low. It's sort of like any other tissue that we remove, there's a tiny subset of patients that end up having a finding that we need to address. Frankly, the removal of the kidney is usually the treatment so in that case, many times there's not much to do, but it's a tiny number. I don't recall the last, but honestly, we had one that ended up having cancer and it's a very small number hence it's so uncommon. It's not something that we counsel patients about aggressively we don't say, you know, be prepared for your path result. You know you may have cancer it's not that kind of a discussion. It's not something we're looking for necessarily.

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Gillian: Okay, since many PKD patients also have liver involvement. Katherine's question says, how does PLD, polycystic liver disease, she says she has a large cystic liver have bearing on removing the native kidneys.

Dr. Scalea: Anatomically, we avoid the liver and the cysts, if possible, sometimes, some patients have a tendency, some livers in patients with cystic disease have a tendency to expand down into the pelvis. And in that situation, cysts may need to be what we call fenestrated or sort of take the top off, lift up the hood, so to speak, remove any of that fluid and have access to the kidneys. It's usually just not a problem. It really is usually not a problem.

Gillian: Okay, that's helpful. Somebody also asked, is it a common problem to have an abdominal cavity filled with fluid after you've had a double nephrectomy?

Dr. Scalea: No, that would be a separate problem. It's a great question. I guess if you don't live in the LA like I do or see patients everyday like Terry, I guess you know, why wouldn't you think that it does, that it wouldn't, your belly it's a weight loss operation. We just did one a week and a half ago, the patient lost 50 pounds. 50 pounds, because the kidneys were that they 50 pounds, and one of the biggest that we've done. And the belly goes from sort of round to concave, you know, and you don't regain the space with fluid it you quite literally just regain what we would say is your normal peritoneum, peritoneal cavity, there's no air in there, your body just can now turn that space into a potential space where everything is, you know, it's air free and everything heals in, there's no fluid.

Gillian: If a liver cyst was kind of accidentally nicked or something, could that-

Dr. Scalea: Not a problem. There's a small number, let me say it. Can it be a problem? Yes. If it was a problem, we would see it, we would address it. There are some cysts occasionally which coincide with some of the small ducts within the liver. And there can be biliary leaks and things along those lines. Please don't be nervous about that. Most of the time, they're just simple cysts.

Gillian: I will see if I could squeeze these last two in I think-

Dr. Scalea: Terry is that mostly, right? Do you have other concerns about liver cysts?

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Dr. Watnick: I mean, not really. I've never actually seen that myself. And I've had, like so many patients get nephrectomies I've never seen it. I did have heard about it when people are having partial liver resections.

Dr. Scalea: It's a different story.

Dr. Watnick: That's a different story. There I've heard of that. That's what I was just thinking, I just wonder but I've never seen it with a nephrectomy myself.

Gillian: So, this question I know a lot of people are curious about. Any advice on finding one of these great transplant centers? Any sources of outcome data, how would you guide a patient who's looking for a great transplant center, obviously, maybe in their area, first. And is there a way to easily access that information for a patient?

Dr. Scalea: So, that is a great question. The short answer is no, there is no good way. The long answer is you ask around through your physician network. I hate to be too ambitious, but I do wonder, Terry, I wonder how hard it would be for a group of us to circulate a list and have it posted on like, the PKD site or something, here are the centers, if you feel inclined to reach out, you know, without an advertisement, but kind of a passive list that would be there may be a benefit to something along those lines. I think that's about it. I don't think there's there is no standard and it's not required.

Let me also say that the outcomes data are not an issue. Let me tell you why. The federal government requires that transplant centers report all of their transplant outcomes that are publicly available, that you can get on your laptop or your iPhone right now and figure out what the outcomes at any transplant center in the United States are. It's a tough business, quite honestly. But the outcomes are excellent nationwide. Really, they're excellent. And so, outcomes matter a little bit. But it's really more about your own personal interaction with your surgeon and your nephrologist in that group. I wouldn't fear, are they going to get the transplant right, part with or without the nephrectomy. That part is relatively straightforward, believe it or not.

Gillian: Okay. And this is just we'll do this as our last question. I just want to remind everyone, that the PKD event staff in the chat has just reminded you to please

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fill out the following survey on Survey Monkey there's a link there for it really helps us prepare speakers and just understand how helpful the information is. So, we would really appreciate that feedback. And this is just a trivia-type question for our last one. What's the average weight of PKD kidneys that are removed at transplant or post?

Dr. Watnick: I don't know. What do you say, Joe? 25 pounds, 20 pounds.

Dr. Scalea: I think it's probably 20 pounds. Real pounds. Like I mean, there like they're really big rugby balls that are like filled with kind of water, imagine that. Now can I just this poor man, Greg Mainolfi has had his hand raised.
[crosstalk] [00:58:44]

Dr. Watnick: Greg worked with us in our PKD center for a summer. Let him also speak

Greg: I am Greg, patient of Dr. Watnick. Living legacy employee, having coordinated transplant with you many a time. I am respectful of everyone's time. You've answered most of my questions. I am just curious, though, like, can my transplanted kidney go in the space of where my native kidney was and would Dr. Alvarez's big mitt be able to fit into that space, I guess?

Dr. Scalea: This is a question where do we put the kidney. If it isn't broken, don't fix it. We do take the kidneys out, that is true. There is space there. There is nothing inherently better about placing the kidney in its native position, versus where we place it for a standard kidney transplant in the pelvis. In fact, what you don't want to do is something a little bit, it's not standard. We perform a standard kidney transplant on the standard vessels, but through the same incision used for the nephrectomy and that's actually it's important for many reasons. Number one, that's how you get standard outcomes, standard procedures lead to standard outcomes. Number two, if we need to do a biopsy of a kidney trying to go through your back and avoid scar tissue in your abdomen and we're not playing that game. When the kidney is in the pelvis it's got better access for Dr. Watnick to order a biopsy and make sure that the kidney looks like it's supposed to look under the microscope.

Greg: Fantastic. Thank you.

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[Audio Ends] [00:45:00]