Nephrectomy Surgery - Understanding Risks and Benefits

All right, I think we'll get started.

Everybody ready?

Ready.

Welcome everyone, and thanks for joining us For Nephrectomy Surgery -Understanding Risks and Benefits.

My name is Nicole and I'll be your host throughout this session. Before we get started, post any questions that you have into the chat and we will have some time for Q&A at the end of this session. We ask that you do keep your microphone muted, so that everyone will have good audio quality throughout this presentation.

I'm pleased to introduce you to our speakers, our panel for this session, Dr. Terry Watnick is the John be and John H. Sadler, professor of Nephrology at the University of Maryland, school of medicine, she graduated from the Yale School of Medicine and completed Internal Medicine training at Yale-New Haven hospital before moving to Johns Hopkins, where she received clinical and research training in nephrology.

Her laboratory focuses on understanding the factors that cause aneurysms and ADPKD. And she previously served as the chairwoman of the PKD Foundation Scientific Advisory Committee and was a member of the Board of Trustees.

Dr. Scalia is an associate professor of surgery at the University of Maryland school of medicine, as well as I multi-organ transplant surgeon, researcher and innovator.

He graduated medical school at the University of Maryland and studied transplant biology at Harvard University, before completing his transplant surgery fellowship at the University of Wisconsin. He's the director

the kidney pancreas transplant program at the University of Maryland which he grew 200% to become one of the nation's largest SDK programs. Dr. Scalea received International notoriety in 2019 for pioneering the use of

drones in Transplant and was named innovator of the year in 2019, entrepreneur of the year in 2020 and winner of the American Society of Transplantation Visionary award in 2021.

Joining, Dr. Watnick and Dr. Scalea on the panel is Greta Ellis. She is a PKD patient, and she's going to be sharing her story with us, and just a little bit. Dr. Watnick, I’d like to turn this over to you.

Okay, I'm going to share my screen.

Okay.

Hold on a second.

Okay, can everybody see this?

Okay? Yes, yes. Okay.

I just want to thank the organizers for inviting me to participate in this panel.

This is I think a really, really important topic and one that I think my patients ask me about all the time.

So thank you, and thank you to everyone who's joining as well.

So I'm going to that's the disclaimer.

I have no disclosures.

And so, I just want to start out by pointing out what I think is very obvious to everyone and what you all know. Sorry about that.

But the symptoms of polycystic kidney disease are related to kidney size, okay?

And so that's shown schematically over here, you know, the kidney grows over time.

And these cysts are what really cause all of the problems that other PKD kidney, including high blood pressure the increasing pain and distension, cyst ruptures, blood in the urine, infections Etc.

So when people approach the need for a kidney transplant, it's kind of a natural question to ask. Can I get these kidneys removed if they don't work anymore?

And so before I even get to that one of the questions that I'm often asked as well, what would happen to my own native kidneys after your transplant, if I don't get them removed. And actually there have been a couple of studies that have looked at this question and it actually turns out that the volume of the Native kidneys tend to decrease after a kidney transplant.

One of the larger studies was done at the Mayo Clinic where they looked at 78 individuals who had Imaging before and after transplant. And but however they were on a lot of different immunosuppressive regimens that the Imaging was done at different times so it's not a perfectly controlled study but you can see here this is one example of pre-transplant and six months after transplant, you can see that there is some small reduction in the size of the kidney, it turns out, when you look at people over time that most of this, decrease actually tends to occur in the first year and then it kind of slows down. And so what I want to point out is that these kinds of studies are retrospective, meaning that we look back over time.

So people have all different kinds of ways that they're treated. So it's not very well controlled. And if you see here this is a chart looking at the change in kidney, volume of all of these different participants.

And you can see that there's kind of like it's all over the place. The vast majority May decrease a little bit but then there are people whose kidney volume, they kind of level out and then go up over time like this person over here.

So I think it's not a hundred percent clear, but probably when you look in the aggregate, a small number of other is a small decrement in the kidney size. But what I want to point out that even if the kidney size decreases by 20%, there's no guarantee if the kidney really going to address a lot of the pain and discomfort, the infections, or the bleeding.

So what about if you have decided that you do want to get your kidneys taken out and you and your doctor decide that it's the right thing, a question that really often comes up is when should they be removed?

And, of course, there's like three different ways that this could be done.

One possibility is to have the kidneys removed before the transplant. So the potential advantage of this is that there would be less risk to the transplanted kidney.

But the big disadvantage is if you are not requiring dialysis at the time, then obviously you're going to need dialysis, if, if you do get your kidneys removed. And this is really a big, I think, a big factor that makes most people not want to do this and then yeah.

So the other possibility is to have the kidneys removed after a transplant, right?

So you get your transplant and then you get it removed.

So, the big advantages, obviously, that there's no need for dialysis, but the potential disadvantages if you go through surgery, after you have your kidney transplant, would there be any injury to the transplanted kidney, and the big disadvantage of both is that you obviously need two surgeries one to remove the kidneys and one to get the transplant.

So had at least in comparing these two approaches, there was one study that did this. This was done at the Mayo Clinic and a the Mayo at least at the time of this study was done, most kidneys were removed after transplant. So again, this is not well controlled. But they compare those individuals that got their kidneys removed before the transplant and those after the transplant, and then looked at a bunch of different factors to see what the complications were.

Those are all listed here, but the long and the short of it was that the overall complication rate was lower for those people getting their kidneys removed after the kidney transplant.

So, it was 26.6% versus 48, but in no situation did that affect, you know, the overall survival of the graft. So, the last possibility and the one that I think a lot of patients really like is having nephrectomy at the same time as you have your transplant.

So this has really obvious advantages.

It just would require one surgical procedure as opposed to two. There's no need for dialysis, if the transplant is pre-emptive. So it's all done at the same time and then I had found that at least for my patients that they found there's a lot of patient satisfaction with this. The potential disadvantages of course are that answer your you'll see when I turn it over to Dr. Scalea, that you there's always the possibility of unanticipated, surgical complications, it requires a longer operative times, a longer hospital stay, possibly increased need for transfusions, and obviously if your kidneys are working at all, you're going to lose, residual function, renal function. But that's true regardless.

So what I would say in summary looking at this is that different transplant centers, and you can probably know this from talking to people that you meet, have different approaches. Some feel comfortable doing it one way, others feel comfortable the other way.

And I think it just really depends on the experience of the surgeon and the transplant center.

The one thing I kind of skipped over, I think I lost the slide there is that the patient graft and patient survival are not really any different whether you leave the kidneys in or take them out.

So, additional questions to ask I guess or that I that come up sometimes as what about taking out just one kidney versus to and whether the native nephrectomy can be done laparoscopically. Technically, I think it's more difficult but I'm going to let Dr. Scalea as a surgeon, comment on that. And obviously if it gets complicated there's always a possibility of converting to an open nephrectomy.

So I'm actually going to stop there. That's kind of the medical overview.

I'm going to go back. I actually realized that I skipped one slide somehow back.

Somehow it got deleted. I don't know why.

Okay, what I did want to say is that everyone, what I think we all agree on is that the, the usual indications for removing kidneys are a, if they're very, very big and surgically the surgeon feels that you can't put in a kidney. Two, if you have current infections because clearly once your immunosuppressed the risk of infection goes up. 3 is recurrent bleeding.

So as people, you know, probably better, you know, know that the cyst can rupture and bleed. And when people start to have this happen, a lot that's another indication to remove the kidney. And then last, if there's any suspicion of cancer in the kidney.

So I want to end there but you know, a lot of people may not have any of those and still may want to have their kidneys out. So with that, I'm going to turn it over to you, Dr. Scalea.

Wonderful Dr. Watnick. Thank you so much, and if you could just Advanced one. So I'm going to just Echo, a couple of thoughts that Dr. Watnick made in some Concepts and highlight that, we've learned a lot about the way that we do these surgeries.

We’ve learned a lot over time that there are different ways to do this.

We can remove kidneys before, we can remove them during, and we can remove them after the transplant. The most common reasons to remove them are pain, bleeding, and infection and to that point, from a transplant

Standpoint, we don't want our patients on these immunosuppressive drugs, to be at risk for infection after their surgery.

So you know, one of the benefits of having them removed at the same time or before the surgeries is that those risks are gone. So I want to highlight that those are, those are real surgical risks that we take into account.

There have been a number of different studies that compared removing of removing the kidneys at the same time and removal of the Native polycystic kidney is at the same time as the transplant, and the outcomes are impressively good.

And these data come from the University of Wisconsin, the University of Maryland and other major centers around the United States.

What you see here are some data taken from 2016. A paper published in transplantation, one of the preeminent journals in our field and we can see that if you have your kidneys removed at the time that we do the transplant, the surgery takes longer.

Now we know that, for sure, that's what you see on the top line.

There's also more likely to be some blood loss during surgery and potentially the number of units of transfused blood and those, those are really sort of the primary technical differences between the transplant, the living kidney alone and a living kidney donor transplant with polycystic kidney disease.

And let me take that as a moment to also highlight that we typically do a bilateral nephrectomy or we remove the polycystic kidneys in the context of a living donor kidney transplant. It’s little bit different than a than a deceased kidney donor transplant.

We talk about that separately.

Patients also tend to spend a little more time in the hospital. That's the final line there on the left leg to stay tends to be a little bit longer for patients who have their kidneys removed and why is that? They're both getting a kidney transplant that's true, but there's more surgical time, manipulation of the intestines, and it's a slightly larger incision. And so pain control in the initial operative period is a little bit more intensive.

But beyond that the results after a bilateral native nephrectomy, again, the removal of the polycystic kidney, plus the transplant, in the long term, the results are better than they are for kidney transplantation alone.

And so that's really interesting and potentially related to the underlying cause of kidney failure, but you're going to do quite well with this operation. Again, getting back to my first point that we've learned about lot about this operation over time, we are very comfortable doing it, and it's well by tolerated and patients do excellent.

And so with that, I'll conclude my comments.

I think we want to focus on answering any questions from the group and I know we have an opportunity to hear from one of our patients, which is exciting. And so let me conclude by saying, this is a wonderful operation in a wonderful opportunity to have a single surgery and to get a transplant while you also remove the risk of pain and infection from those, those polycystic kidney disease.

It's well accepted in the community and the results are wonderful.

And so, I'll turn it back to Dr. Watnick at this point and the and the, the organizers and look forward to helping answer any questions.

Okay, so I think we'll turn it over to Greta Ellis, so great to have you.

I don't know, I guess everybody can see this.

I'll just turn it over to you and let you tell your story.

Thank you so much.

Thank you guys for having me.

It's a great opportunity to talk about a nephrectomy.

It's been a while since I had mine, but first, I'd like to start out the saying, of course, ny name is Greta Ellis. I live here in San Antonio, Texas. And I volunteer with the San Antonio chapter at PKD.

And I've been enjoying being a part of that organization. It's a great organization. I just want to say that off the top.

But I was diagnosed with PKD when I was 30 years old, I knew I had it, it was in my bloodline, of course, and I had basically my father died at the age of 39.

And that's when, you know, we really, were focusing on the PKD and problems with it.

I'm 55 years old now.

I've been living this long with PKD, and I started dialysis in 2004.

And my nephrectomy - bilateral nephrectomy was done in 2008.

I was having a lot of pain.

My kidneys were very, very big. A lot of pressure in my hips and in the front part of my thighs, I don't know if my kidneys were sitting on nerves or what, but I could only walk or stand for just a few minutes, and then I would have to sit.

And I was already on dialysis. So I talked to my doctor and I was like, you know, hey, can I have this procedure? Because I already kind of did the wrong thing, Google everything, I Googled and found out you could have your kidneys removed and I thought, oh wow, that's for me.

I just knew that was for me.

So I asked him if he was like, well, you know, we'll run the test and see how you are and get you ready for surgery and I had my kidneys removed in 2008 and I was the best thing that I could have ever done within this PKD journey. Because afterwards, I felt so much better. I had so much energy, so much more strength, and so much more of a better, emotional upgrade too. I just felt, I never was down about being on dialysis, but just being after to feel better and do more.

I was able to start exercising and weight loss and a lot of other things that came with that, but I am, my doctor had explained the risks in to me like Dr. Scalea was saying, you know, there's always a risk of infection with any type of surgery and anything like that and I would like to say if anybody that is contemplating a nephrectomy going into it, you know, please understand it is major surgery.

I mean, I was cut from hip bone to hip bone, so mine were so big to get them out.

So, you know, depends on who you talk to your doctor and they see, you know, how big they are.

And if you know, they actually once I told he thought it was a great idea.

You know, if I was willing to go through with it, I wasn't having any of the cyst burst or, you know, the blood in urine or anything like that, but my mostly was from a comfort perspective.

You know, I was just in so much pain. And I wanted to move around better, but I would like to say, you know, if you contemplate a nephrectomy, make sure you have someone that's available to you after surgery, because I did, I relied on my mother was able to come back then.

You know, you're going to need help moving around and getting around and you know, things like that, you're going to need the help. But for me, it's been a life changer, you know, that was in 2008, push forward to 2021 here. I was transplanted in 2017, which was awesome.

So I'm three and a half years with my kidney and everything for me has been going I mean, just uphill from here.

Of course, you know, the immunosuppressant therapy and things that come with that.

But just being off dialysis. And without having those big, huge kidneys has been just great for me.

And I would like to say, when I had my kidney removed, I lost almost 30 pounds.

One of my kidneys was 15 pounds and the other one was 12.

So that's how much weight and volume I had in my stomach area in my stomach was way past triplets. It was very, very huge. And if anybody has any questions for me about the battle afterwards, so how I'm feeling now, I'm, you know, a few years removed but for me, I really talked to the doctor and you know, he told me the risks, the benefits and I often looked back and reflect on it, I don't regret it at all. Every moment of the recovery, for me, was worth it.

And if you guys have any questions, personally, I'll be willing to answer. And I just want to say thank you guys for giving me this opportunity to talk and to let people know, you know, here you are. I am after nephrectomy and everything went well, for me, so, it's just been awesome.

Thank you, Nicole, for asking me to participate.

Absolutely.

Thank you, Greta, for sharing your story.

It's so wonderful to hear that you're feeling better and that, you know, are doing well.

So thank you for sharing that.

And also for offering to be available, you know, to connect with people. I think that's also important.

So we do have some questions. So let's get into that.

If you have more questions, please type them in the chat box and we'll get to as many of them as we can.

The first one is what do we know about the reasons for the reduction in total kidney volume after (poor audio) your native kidneys.

I think we don't know very much at all, to be honest. I think that, you know, whether it's related to the type of immunosuppression I think is one question. You know, whether it's scarring, you know, you just get fibrosis as the kidneys fail.

I think that's another possibility and so maybe the size you know, gets smaller from that but I don't think I don't think we have like a concrete answer that I can give you because in some cases the kidneys also get a bigger you saw that on that slide I showed where in some people that happens.

So I think, you know, to really get at that question, maybe we would have to do more controlled studies. You know, take people who are all getting the same, you know, you know the same immunosuppression look at it that way, check MRIs it very fixed time intervals, like right before.

So, for example, in that study, I kind of glossed over it, but if you've been on dialysis before, before you get a transplant, actually, the kidneys apparently grow during that time, so that the decrease in the kidney volume may be not quite a significant because the kidneys are starting off at a bigger point.

So, you know, there's a lot of factors there that I think we probably could understand a little bit better.

I hope that answers the question.

Yeah, absolutely.

What kind of a long way to say that?

I don't think we know for sure but that's okay.

I think that was all very good and interesting information. I did not know that about dialysis in the kidney so that was interesting.

What about Auto blood transfusion prior to nephrectomy surgery to avoid a transfusion.

I can take that one. So Autotransfusion is possible if you're if you're at the if you're close to your Center and you can bank blood in advance, it's a possibility, but as Dr. Watnich will describe, patients in kidney failure have a difficult time making red blood, and so frequently they'll have anemia going into these cases.

Perhaps not quite as bad as for folks who've been on dialysis for long periods of time, but it's still real. And so I think it's not something that we, it's not something we routinely do because it's not frequently not an option. There are also logistical challenges with quite literally banking your own blood and making sure it's available and that it doesn't expire right? Because the blood can only last for a month or two in order to get it in. And during that time, you're supposed to be able to rebuild your own blood supply. So that's not something that we commonly do.

It's possible.

I don't want to, you know, everything's possible, but it's not usually something we do.

And I also want to highlight that the transfusion rate may be higher but we still do not typically transfuse, so it's not like you're going to go into this case and expect to require a transfusion. I mean I think we'll talk to you about that.

We will expect you to be prepared for that. But frequently we do not need to transfuse. Is that helpful?

Yes, absolutely. Thank you.

So I have a comment here about, you know, experiencing an advantage to having nephrectomy surgery at the time of transplant.

And considering like, is it, is it more rare now that it used to be? Do you have any data that shows how often people are able to receive a nephrectomy at the time of transplant?

Yeah, I don't, I don't, I don't know what I, what I what I can say is that because not every Center, does it, you know, there's some major centers around the country that do it.

The University of Maryland and University of Wisconsin, I believe Georgetown does it, but you know it's not as common an operation issue you might you know if you got really have to be at a major Centre. I think most major centers would entertain it at a minimum if that were a consideration.

It is more accepted, it's well described in the literature based on some of the studies that I shared today.

And of course, not quite a litany, but a number of others, it's quite safe.

In terms of the outcome I saw, there was a second question about what outcome measures are we really looking at? When we look at patients who had a had a kidney transplant, specifically, a living donor kidney transplant for polycystic kidney disease and kidney failure. We compare that with people have a living donor kidney transplant for non-polycystic kidney disease. Transplants after polycystic kidney disease do better.

And again, that's probably related to underlying disease. I think these patients, take good care of themselves. I think that's excellent. When we look at patients, who had a nephrectomy at the time of their transplant and we asked them what they thought, 100% of respondents agreed that they would do it again. And I think that's very telling. I think that says that's important. And let me one final comment about the cadence of why distinguishing one from another. You know getting multiple surgeries is tough. I mean, it's a huge chunk of your life in a huge chunk of time.

It's challenging for your family, it's challenging for yourself, and being able to do this in one shot really is an advantage in terms of your just generalizing your own care.

So several questions in one.

Sorry about that saw them coming in.

That’s okay. That's very helpful. I appreciate it.

There is some conversation about donating your native PKD kidneys to research from the PKD Foundation side of things, I can say that we do assist with that. Our Research team does, you can contact us if you want to donate your kidneys, do either of you want to comment about donating your kidneys if you’re having them taken out.

Yeah, we, I’ll just say that here at the University of Maryland actually

I collaborate with Dr. Scalia, and that team there. So we actually go into the OR and get the kidneys directly when people consent. Because the sooner you get them after they've been taken out the more the cells are preserved.

So we are actually doing that and we are making cells and tissue to give out to the research Community.

That's a part of the NIH funded PKD centers program that I'm involved in.

I know the Foundation, I know, I know Nicole that you guys also take kidneys.

Well, not to our office, we can't do that.

I know, you know, you help you help investigators get them.

Yes, we do.

I say that because when at our office in the elevator, one time, someone from another office in the building asked us about that. Do you have kidneys up there?

We were, like, no, we don't. So we don't take the kidneys directly, but we do help that. So you have questions about that you can certainly email our office and we can get information.

I saw one question kind of float by, Nicole, about hypertension after having a native nephrectomy and somebody was noting that their blood pressure went down and in fact that at the series I looked at that as a frequent observation, that blood pressure goes down because at least before a nephrectomy, hypertension and PKD is thought to be directly related to the, to all of these cysts in the kidney and upregulation of, you know, hormones that that cause high blood pressure.

So I forget the question was way up there. But yes. Oh and Risa Simon said she stopped her blood pressure meds the day after the transplant.

So I think that is a frequent thing that people notice and in the studies that I've looked at and I think that that's borne out.

Yes. I can attest to that cuz I haven't been on, I had my nephrectomy in 2008, and no more blood pressure medicine for me since then.

I would only comment that surgically, you know, we see, presuming that the cause of kidney failure is strictly related to polycystic kidney disease or in that there are no other underlying issues, diabetes, under underlying high blood pressure, you know, there can be some other issues that will adjust, but presuming that it's really that everything is really related to the causes of kidney disease, frequently patients come off their blood pressure medicines as Dr. Watnick had suggested.

Switching gears just a little bit, but I think it's a great question.

Is it difficult to diagnose kidney cancer because of all the cysts in the kidneys?

That’s a good question. I will say I have seen that a few times and the way I, what alerted us to it was kind of recurrent cyst bleeding, like you know, in the absence of any precipitating event sometimes, you know, and it was recurrent and so that does need to be looked into, you know, whether you're going to find a small focus of kidney cancer, kind of depends on how well the pathologist goes through all of that. And as you have seen with these kidneys, you know, I think you know, I don't know how frequent it is, it does happen.

Most of the time it's kind of confined to the wall of these cysts and it looks like a papillary growth.

Go ahead, Jo, maybe you have more.

I was just going to comment that surgically, I don't mean to sound like the uninformed surgeon, but the treatment is to remove the kidneys. So right? So you know if and when it is found, you know, the benefit here in is that the kidneys are actually gone. And so, you know, I don't think I can recall a situation where we had, yes it can be difficult to identify in these, I mean these samples are huge, right as Dr. Watnick was describing, but they are out and so you know, if there is something identified, you know the definitive therapy has been applied.

Yeah, completely agree.

Hey, thank you.

Do Native kidneys stopped, working after a transplant?

I think they probably, I mean, maybe not initially, but you know, with the, you know, the probably your GFR, if you, if you're having a transplant in the first place, is probably pretty low to begin with and all of the medications that you're on may, probably cause that in the end.

I'm guessing, but I don't know if it's been looked at formerly that probably you lose whatever function you have.

It's hard to know because the, you know, the yeah, you're making you're making urine, right? And then you sort of never stop making

urine and then, you know, but the GFR increases and we attribute that to the kidney.

And so we don't really know, you know, I sort of think about it as two sort of, two curves on a graph where the GFR is the kidney function is decreasing as a result of the Native kidneys and then increasing as a result of the new kidney. And, patients go on to live a beautiful, happy life without the need for dialysis. It's a result of the new kidney.

I do think I want to, I want to highlight this. The medicines that we put patients on after transplant which include calcineurin inhibitor, specifically tacrolimus, or one of the derivations there in, can injure

the native kidney, they can injure the transplant kidney as well.

And so, if you have an already at-risk kidney, and then we go on some of these medicines the likelihood that those native kidneys function, well, or at all, is quite low in a long-term. And so I don't, you know, the native kidney probably do stop working.

Yeah, so the question, like, if you are trying to say maybe oh, like, oh, like would I be losing a lot of function by having them taken out?

I kind of don't think so. You know, you know where it would be a problem is if you're not on dialysis, you're not going to get a kidney in the near term then, yes, then it's significant but I think if you're getting a transplant probably that loss of whatever small amount of GFR, I think is probably not.

I would guess I don't think it's a significant factor.

Yeah. So we have a question here.

Is there a benefit to having your PKD kidneys? In case the new kidney were to fail and they would be like a backup. So what essentially you're saying is no.

Yeah, I don't think over time. I mean, yeah, I think that's unlikely.

No and I do want to highlight that there's, you want to do these transplants before you get sick, before you need dialysis, right? And so, this is gets back to that concept, to sort of, seeking it out. And how much are the really are the native kidneys really helping?

We're at the point where the GFR is really less than 30 and really, under-20s what gets you on the transplant list. It's time to consider a long-term strategy which is transplant and so, and I will also comment that I know we're getting into some of the science here.

If you look at patients, who have had a transplant, who where their native, kidneys are not removed polycystic and otherwise, and, and their kidney transplant fails after five or six years or 10 years or 20 years they make they make note very infrequently do they make any urine. And that I think is attributable to some of the pharmacologic side effects that I described earlier.

Getting back to the fact that I think that the native kidneys really do in quotes shut down as a result of process, but also the drugs.

Okay, so here's a good one, does a very large liver due to PLD interfere with the ability, for a nephrectomy due to the liver resting on large polycystic kidneys?

I can take, I said, oh, so, the short answer is no, the long answer is yes.

Um, it almost never interferes, the two organs are separate. It's really rare. That the cysts quite literally are conjoined or causing an anatomic challenge with removal.

We're able to do that.

I will tell you occasionally, the livers in patients who have polycystic liver disease are incredibly large and they can go all the way down to the pelvis.

I could count the number of times I've seen that on one hand, maybe with just two fingers. It's not common, but and those lists those sometimes those cysts in the liver require fenestration, which means you have to open them up and sort of debulk them a little bit, but not commonly where you almost always able to get the kidneys out without much Challenge from the liver.

Okay, can you talk a little bit about recovery, so Greta you, maybe you want to, also someone also wanted to just to confirm you, I lost it.

Now, let me go back. Where is it?

You had your nephrectomy, tell us again.

You had your nephrectomy when? And then your surgery when? They wanted to confirm the number of years that you were on dialysis, here it is.

I was like, okay, I was on dialysis for almost 13 years. I started dialysis in 2004 was transplanted in 2017. I had my nephrectomy in 2008, so it was quite some time between my nephrectomy and my transplant.

And can you want to talk a little bit about your recovery?

How long did your recovery take? You need to have some support.

Yeah I will suggest somebody there for you. Like I had, I needed help getting up and down out of the bed because of the stitches in the sutures and I needed help, you know, going back and forth to appointments and things like that.

It was painful. I mean, not going to sugarcoat it. It was a little painful afterwards, but and I'm not big on pain meds. So it's probably my fault, but, you need help, you know, moving around and getting around because you just don't want to just lay there. You know, you gotta get up, you gotta get moving, keep your blood flowing. You don't want to get blood clots and things like that, and you want to do exactly what the, you know, the doctor prescribes you, you for your discharge, make sure you’re keeping your lungs clear.

But I would say, I probably was in bed probably a week laying down. Second week, I'm getting up, you know, taking a few steps around the room, you know, things like that.

So I think I'm can't really remember. It's been so long but I think I got my sutures removed within that month.

I do believe so it wasn't, you know, a long time. But I just feel like that first week is probably really when you're going to feel it.

In the second week, you'll be able to start moving around more.

I'd like to qualify that. So that is a beautiful story, Greta.

And I mean, can't I mean, you've lived through it and you hearing your stories. Also wonderful. I really appreciate you taking that time.

Patients, who have their kidneys removed before they get their kidney transplant, have to get through the operation, like, Greta did without kidney function.

There's no kidney function, and that is organ, failure, that's hard for your body to cope with. And so the pain and the swelling, and the fluid, and the dialysis and the and the it's hard, that's tough. If you get your and so you saw some of that data that Dr. Watnick describe, if you get your kidneys removed after a transplant, you're in the hospital less time, the recovery of shorter. Why?

Because you don't have kidney failure. If you get your kidneys removed at the same time, the simultaneous nephrectomy and kidney transplant.

It's very, very similar to the latter.

You have normal kidney function. You're able to get up and move around.

You're not, you're not facing many of those fluid overload challenges, high blood pressure. It really is kind of a different experience and so I do want to qualify that a little bit.

I'll also say that I do think, you know, we gotten better at this.

It's something that we're quite comfortable with.

And if you're at a center where the team knows how to do this, and it's comfortable and familiar with it, I think it'll be pretty smooth.

It's pretty smooth.

Yeah, I want to say to I think I was only in the hospital for like three days. If that helps anybody.

Can you talk a little bit about pain management? There's a comment from someone that is intolerant to narcotics and is very concerned about the amount of pain.

So how do we, how do you manage pain after the surgery?

I did very well, but I would say, you know, other than Tylenol with codeine. I think that's all I took.

And I only took that, you know, maybe the first few nights like that and then it was Tylenol. And I mean, just keep your body.

I mean, I was still having to get up, of course, and go to dialysis and things like that. So, you know, I did a lot of things, like meditation, but the pain was never overbearing where it brought tears to my eyes, you know, or anything like that.

But I was taking my Tylenol with codeine and then after that, I was just taking, you know, the straight 500 milligrams of Tylenol, but, you know everybody's different when it comes to things like that.

Because, you know, I remember, when I had my nephrectomy, and they were coming in and telling me I wasn't pushing my pain pump. I was like, well I'm not in pain, you know, but you didn't just thought maybe I was suffering but I wasn't.

But I mean, it just depends on your, you know, pain, tolerance level, you know, depending on what you're going to need.

I know this is not a class, I promise that we're going to not make be to science driven, but there's been a huge change and shift in our understanding of how we use narcotics for patients after surgery, an enormous shift. And let me rest, keep everybody's mind I want to make, keep, rest assured, everybody knows what they're doing when it comes to pain management after surgery. And we're much better at it today without narcotics than we used to be.

And there are, there are major hospital and provider initiatives to reduce the requirement for the use of Narcotics after surgery. We don't want the patients on narcotics after surgery, it actually ends up causing more problems than it does help.

And so there are, we have protocols for Rapid discharge from the hospital even narcotics sparing. At the University of Maryland, we just implemented one for pancreas transplantation with the kidney transplant, which in some ways is akin to what we experience here.

So we can minimize, for those folks who don't want to take them, who are not interested, you're in luck. We have protocols that will allow you to get through these procedures with minimal narcotics and we can do that with great results.

Thank you.

We have several questions about laparoscopic surgery. So is that pretty common? Do you think it'll be more common in the future? What can you tell us about that?

Yeah, it's these kidneys, I'm not joking, are like they're the size of two rugby balls. Like I mean, they're this big so trying to take them out laparoscopically is that you use the, yeah, I mean you have to like mince them inside the patient and take them out piece by piece and like that we don't do that because it takes more time and it's more effort. You also want to make sure that these procedures are controlled and safe and generally speaking, it's not done, generally speaking it is not done. Does that mean it's impossible? Now everything's possible, like moving organs by drone, but doesn't mean that we do it every time that we do a trick. So my point being that it is probably not going to be. It doesn't make a lot of sense. They can actually add surgical time. They can actually increase the risk of the surgery.

Okay, thank you.

That was interesting.

I haven't heard that spoken to quite like that, so I appreciate that answer. Do you need to have an ultrasound or an MRI to determine if a bilateral nephrectomy is needed?

This might be to see if you have room for a transplant, I'm not positive. But you might want to touch on that too.

Sure. I'll just keep it short because I know we're running out of time. Cross-sectional Imaging or CT scan or MRI are the preferred tests and we do that so we can understand how much of this how much space is being taken up by the kidneys in combination with a patient history.

Early satiety like, you know, can you eat a full meal and a history of bleeding and infection? Those are what we use to determine the size. Does matter in terms of, you know, ability to put the kidney in.

Okay, I'm just scanning down through here because we do have just a couple more minutes.

Can you talk a little bit about hernia repair?

Yeah, so patients with polycystic kidney disease do have some form of connective tissue disfunction which is part of the reason that they also develop cerebral aneurysms occasionally. And we'll ask patients who have polycystic kidney disease to get MRIs of their head before they undergo surgery soon can understand the risks, right?

I think we've already discussed that in other sessions I presume.

That probably predisposes patients that get surgery to some hernia rate that's higher than patients who do not have polycystic kidney disease.

If you develop a hernia after surgery, it can be fixed potentially laparoscopically or can be fixed through the same incision that you've already had. And so it's usually not it usually didn't add any additional incision, it does occur.

They're hernia rate is low. It's probably the, I'm sure it's less than 5%.

Well, let me say this probably less than 10%, but it's in that ballpark.

Okay. Very good. I believe that's all the time we have, but I really want this question to be answered what happens in the body in the Gap. Like, how does the body fill the Gap after you take those kidneys out? Do you mind getting that one before we go?

Sure, your body is made of 100 trillion cells that grow to full adult size and only a matter of years. It's really, really, really smart.

And it's incredible, you take out these massive kidneys and they act a little bit as they sort of increase the size of the belly a little bit, but you would be shocked. I mean, you put you close the belly and it's like they weren't there.

I mean, it really is like they weren't there.

There is, there is no space, there's no fluid there. It's what we call, we would be we would be eliminating what we would call a potential space but no, that's not replaced by fluid your body heals it up.

It’s remarkable actually.

That is very interesting.

Nicole, could we ask Dr.Scalea one more question, which is, is there any reason to do a single nephrectomy instead of a bilateral nephrectomy?

Because, a good question.

So I remember at one situation, every surgeon does, every doctor, does this right, this one case?

So we went in with the intention of not removing either kidney, there was not enough space and we literally needed to remove the kidney we were removing the kidney on the right, so we had to remove the right side kidney. In that case, you can remove one kidney, there's no problem doing that.

I would suggest that if we're going to go through the time and effort and the incision and the pain and the recovery of removing one where there is risk of bleeding, cyst rupture, and other complications, as well as the increased surgical damage, going back to remove the second kidney in the future, i.e. a second operation.

It makes sense to remove them at the same time.

And so it's thinking linearly, it's usually better to just remove both as long as you trust the new kidney that's going in and in a living donor kidney situation they have nearly 100% graph survival at one year.

So, you know, you can, you can sure it would probably be the right one, but I wouldn't recommend it. And I think it actually puts the patient at more risk.

Thank you, I usually say that as well.

You're going through all the trouble, to leave a kidney in that's going to cause problems down the road, seems.

Yeah, absolutely.

Well, I so appreciate all of this information.

This has been fascinating and I've learned a lot.

I bet I'm speaking for everyone when I say that.

And I do appreciate there's a lot of comments about how well people are doing after their surgery and thanks for sharing your stories that makes all of us feel a little bit better about what we might be going through later.

So thanks for putting that in the chat and sharing your outcomes.

I just wanted to thank Greta for just the wonderful story as well.

Absolutely, yes, thank you.

Thanks to all of you for answering questions, telling stories, we just appreciate it so much.