

Janet Gitterman: Thank you, Wayne. I'm Janet Gitterman just a little intro about me. I'm right now retired. But I had spent my career as an art therapist and clinical social worker. I live in Northern New Jersey, with my husband, who I'll tell you later about was my donor. And my two adult children are out of the house. One of them also has PKD. Now, I'm a peer mentor with the PKD Foundation. And I've also gotten involved with the New Jersey sharing network, which promotes education about organ and tissue donation.

So, my story with PKD began in 28th 2007. And at that time, I became the second in my family to be diagnosed. We think that my father must have had a genetic mutation that caused his, and he was diagnosed when he was 70. I had been just turned 50. When my diagnosis happened, I had just gone for a routine physical. And I came home and there was a message on my answering machine.

The doctor wants me to see a nephrologist because my creatinine was high, it wasn't normal. So, I did go to a nephrologist. And when I was diagnosed, my GFR was at 44. And I was stage three, I really didn't have any symptoms other than my blood pressure climbing. Sorry, it had always been low. But I never had like terrible pain or cysts that bursts or UTI infections. So, my kidney function was a very slow and gradual decline.

And as I moved through stage four, I was developing more fatigue. I also developed anemia, it was not due to low iron, it was due to the kidney had stopped producing works wasn't producing enough of a certain hormone. And so, I was treated with Procrit injections to help raise my hemoglobin. And as I went down and function, I had to start watching my diet more, I've always watched my salt intake, and I also had to stay away from foods that were high in potassium, and also, phosphorus.

That was a little difficult. So, in 2019, I hit that magic number, where my GFR went down to 20. And I decided between two transplant

centers, just decided to take the one that was local to me, which had a very experienced inactive staff done several, several hundreds of transplants. So, I got all the testing done. And I passed the evaluation and then it was time to find a donor.

My goal had always been to try to get a living donor so, that I could avoid going on dialysis for people who offered to be tested for me. And my husband, Michael was the first we found out he had the same blood type, which was great. And we also found out that on a scale for matching tissue, I think it was there's like a six out of six match if you're an identical twin.

We were only we weren't zero I had a fix in the match. But the transplant team reassured us that the anti-rejection medication was much better than it had been and so that wasn't really a deal breaker for him to donate to me. So, he continued his evaluation, and we were finally deemed a match. Michael, do you want? I'm going to take a little time to have my donor, my husband says hello.

Michael: Hi, I'm Michael. I'm the donor. And if anyone has any questions, later on, I'd be glad to answer them.

Janet Gitterman: Okay, thank you. So, last spring, spring of 2021, my GFR started hitting 15, 16, 14. And my friend just wanted me to have the transplant over the summer, but I had plans that summer, which also included our daughter's wedding. So, I said I'd rather really wait till the fall. And we got a surgery day, November 17, 2021. So, that's about seven months prior to the state.

I was still feeling pretty good, up until about three weeks before the scheduled surgery. And then almost overnight, my kidneys weren't working. I just started filling up with fluid. My legs became like tree trunks. And I couldn't even put on a pair of shoes. I went to see my

nephrologist. And he told me that if the surgery hadn't been scheduled, I would have had to be put on dialysis right away.

So, I learned a lesson from that you're, you can go steady, slow and steady, slow and steady. And then you can crash. So, I was very, very fortunate that I had the surgery scheduled. Prior to the transplant, I had told the surgical team, transplant team, I was not interested in being on prednisone, because I already have osteoporosis. So, the surgery was done on November 17, 2021.

When I woke up after the five-hour surgery, I had an oxygen tube in me. And they were talking among themselves. They're saying oh, her oxygen level is down to 80. Got to put her in the ICU and I'm like, you know what's going on? Do I have COVID? Do I have pneumonia? I was like what? So, apparently, as I said I had wanted to avoid prednisone, they had given me something else during the surgery to some kind of globulin treatment.

I don't really understand what it was, but I had a bad reaction to it. And my lungs filled up with fluid. So, I was put on the ICU unit for one day with oxygen. And for the rest of the time, I was in the hospital. I had a respiratory therapist come down and work on me with, I guess I remember them pounding on my lungs to break things up. And I also had one of those air meters where you blow into it and you tried to see make the needle go up.

So, I couldn't do it in the beginning, but I kept at it and gradually my lungs were getting better. So, being transferred to the regular transplant floor. You're well I think in everyone's case scab a lot of stuff going on. You have an IV and you have the monitors. They had put in a catheter during the surgery and a stent. My incision was closed with staples, and I also had two incision drains.

So, I could not get out of bed on my own. I don't think I even tried for the first day or two. But anyway, in terms of the kidney, it started

functioning immediately. And all that swelling that I had within my legs just completely disappeared. For me, my main problem was, I guess from the side effects of the medications, was gastrointestinal, and I had really bad bloating, nausea, and no appetite.

I really, I would order some food for the meals, kind of pick at it, and really just lived on saltines during the hospital. Something else to keep in mind, if you're like the majority of people and put on pain medication, you have the tendency towards constipation. And you have to make sure that you're getting laxatives or stool softeners because you want your digestion to go well.

And I was very frequently asked, have you passed gas yet? Have you passed gas? So, they want you because of the anesthesia, your digestive system is often very slow to wake up. So, on my fifth day in the hospital, I was ready to get just charged, the nephrology, pharmacists to worked with transplant patient's fraud in a huge red duffel bag and said, I have your first month's worth of medication. I was like, are you kidding me? It was really a big bag.

But she said don't worry. There's also a bathroom scale and blood pressure monitor that the pharmacy had thrown in. So, the pharmacist had already filled my pill container for the first week so, that I wouldn't have to try to figure that out. And before I left, I also had to have the nurse show me how to drain one of those incision drains. Because it's kind of like a plastic bulb that gets filled with fluid.

And you can't just dump it in the toilet, you have to measure how much is in there and record it and also record the time. So, my catheter was removed. I went home with the stent still in the two drains and the staples in the incision. And I was unable to shower until the staples were out. So, that wasn't really pleasant. I'm coming home. My sister-in-law was our caregiver.

She had already picked up Michael again, my donor husband, who was only in the hospital for two days. And then she came and picked me up and your team is going to be very adamant that you need a caretaker. So, this was really true since both of us were out of commission. And she did things like laundry, grocery shopping errands writes to our doctor appointments. Something that was really helpful that I had done prior to the surgery was just signed up on a website called mail train. And it's a free website, you can send the link to your friends and family. So, instead of having people say what can I do? What can I how can I help? And you're like not feeling that great to answer. They can sign up to bring it with dinner or breakfast, lunch, whatever your needs are, and you can also indicate what dietary preferences and restrictions you have.

And that was really helpful. By also after my sister-in-law left, I also needed rides to the hospital to see my transplant doctor. And I was able to ask local people for rides. The other thing about grub meal training is you can also order gift certificates on Grub Hub. Okay, meals delivered. So, the first couple of weeks at home, maybe more than a couple of weeks, I really had no energy to do anything or couldn't watch TV or read. I didn't even feel like talking on the phone.

But we had, I was told I have to walk a lot in order to get your recovery go. And so, every day, my husband would say to me, are you ready to walk? And I would say, no I don't feel like it. And he would say, Okay, let's go. And it wasn't easy. I started trying to walk a block. I think because my lungs had been filled with fluid, I got out of breath really quickly.

And just walking up a very slight incline of my driveway was like climbing a mountain. But I did try to walk more every day. Sometimes I could sometimes I couldn't. I also had insomnia and was unable to take naps. So, I was pretty much a mess. Again, I still had all the gastro problems that I had in the hospital with the bloating and no appetite. I

basically just ate crackers and would go through a whole sleeve of crackers in one day.

And now I will try to kind of pick so I could get some protein inside of me. But it was hard. So, post-transplant clinic, you'll spend a lot of time there the first month. My first appointment was scheduled two days after my discharge. And I was really tired. I struggled to get up I decided I'll just go there in my pajamas, and slippers with my drain hanging out. And I remember going into the waiting room and looking around and everyone was wearing normal clothes.

Like oh, am I ever going to get like that? And how many months will it be? But a few weeks later, I was there wearing normal clothes friend driven me was sitting with me in the waiting room and a guy walked in, in his pajamas with his train hanging out, and I said this is his first time and it was so, in my transplant center, I would receive my appointments for the next three months.

The first month I went twice a week. The second month was once a week. And then it went to by monthly every other week. And then monthly labs they're done at every visit. And the nephrologist can make adjustments to your medications based on, what the lab results for. My routine now is every Sunday I sit with my pill container and fill it for the week. In the beginning, I had to look at my list and I looked at the pills and it took a while to get it done. I think maybe the second or third week even I still needed someone to help me. I'm now at the point where I'm able to do it in five to 10 minutes stop So,

Wayne Smith: 10 minutes,10 minutes.

Janet Gitterman: Oh, okay. So, you know in terms of my lifestyle changes after transplant and I'm really way more protected from the sun because the anti-rejection meds, lower immunity, skin cancers are very common. I bought some clothing with UPF protection. I always wear a hat. And I always wear sunscreen. I'm happy to say that last month, which was six

months after my transplant, I was able to go hiking in the Rocky Mountains of Colorado, I was at 9000 feet, and about three or four miles and I was really proud of myself and my recovery.

So, I just want to mention a couple of helpful tips. I would say, don't wait too long to get your evaluation done. If once you have one lab that hits 20, you're good to go. And even if your GFR goes up, you're just put on inactive status, but you continue to accrue time on the transplant list. Which is especially important if you're waiting for a deceased donor. Plan the big idea early with friends and family that you will need a kidney donor. And it's either that or dialysis or both. Just some practical tips for the hospital. I'm a light sleeper.

And I found bringing earplugs and a sleeping mask helps because you're constantly woken up for medications, blood draws your vitals remember to keep on top of the pain, but also that the output of opioids can lead to really bad constipation. So, ask for laxatives and stool softeners, whatever you need. Oh, this was really helpful. I brought a small pillow with me to the hospital.

And it was something I could hold on my incision site, which by the way is in your abdomen if you don't know that, and it was a little more comfortable to sleep. While so going home in the car, the pillow was able to cushion against the seat belt that would normally go right into the incision site. So, as I said before, walking is good for your recovery. And do it even if you don't want to. Don't expect to bounce back right away you had major surgery and your body needs to heal.

Although I mean, you can talk to people about their experiences, which I found really helpful. And I have heard of some people saying especially if they've been on dialysis that as soon as they had their transplant, they felt great. I just saw on the screen someone asked about in a fracture me. And in my case, I had room for a third kidney. So, my native kidneys are still with me. I have three now. But I do know people who have had nephrectomies.

And when you're looking into Transplant Center, that's a really great question to ask what their procedure is, some centers will do the surgery with the transplant all at the same time. And others want you to do the nephrectomy first and others want to do it after your transplant. So, again, it's great to get information. Try to look at more than one transplant center.

I had I was in between two, but some people expand even further. So, thank you for letting me share my story. And remember the PKD program has a mentor program. And it's a great resource for anyone, pre- or post-transplant. Thanks.

Wayne Smith: Thank you, Janet. And you've already answered some of the questions which are fantastic. Please keep your microphones muted. But please continue to put questions into the chat and I'll put them to giant one by one. You mentioned about registering with more than one center, where the doctor is able to determine why your kidney function suddenly plummeted.

Janet Gitterman: No, no, no, it was, it apparently, it happens a lot.

Wayne Smith: I was lucky. Yes, I can also I mention that I'm also post-transplant as well, Janet and I were discussing this over email before. So, I'm in a similar situation to Janet as well. So, please feel free to add questions into the chat and Janet can answer them. Would you be willing to share which transplantation to huge carryover?

Janet Gitterman: Yeah, I'm, I'm very close to New York City. And the transplant center is that I used was St. Barnabas and Livingston, New Jersey. I had also looked into New York Hospital in the city where my nephrologist was ultimately, I decided on the local one after the nephrologist in New York, said that lip balm St. Barnabas was just as good and just as many transplants as they did. And it was just so much more convenient for all the post-transplant clinic appointments.

Wayne Smith: Any other questions for Janet? I just added a little perspective, if I may, to the previous question that you answered Janet about, you know, registering for more than one center. And I think I would expand that question a little bit to say, you know, make sure that you are being a good advocate for yourself.

Or if you haven't got if you don't feel you can find someone who can be your advocate. Some people depending on their you know, health care and insurance situations, may not have the luxury of changing centers, but they may be forced to an in-network center. But, you know, if you're not happy with what you're getting from them, don't be afraid to look around, if it's an option for you, because you need to advocate for yourself, you need to be sure that you're getting the right treatment for you and your circumstances. And I think from listening to Janet, I can certainly say that. I speak to loads and I'm also a peer mentor of the family. I speak to a lot of people as well. And every person's story, every person's journey is very different. And you need a good self-advocate. Yeah.

Janet Gitterman: Yeah, really important Wayne. And yeah. I also had started with a nephrologist who didn't really know too much about PKD. And then I switched. I was like, wait a minute, I'm starting to learn more about it than he. So, I counted. And that's fine.

Wayne Smith: Tom's put a great question in the in the chat here, but about those follow-up appointments. And do you need to stay close? I did, Janet. I'm assuming you were close anyway.

Janet Gitterman: Yeah. I was close for the first three months, and four months, and then I was able to travel. Oh, one thing I wish I didn't mention, but the pandemic was great training for a transplant. I had no problem adjusting to wearing a mask. I was already doing that. Yeah. Not going into stores. Keeping socially distance.

Wayne Smith: Yeah. Yeah, I can concur with that. Yes. And it was the same for me. In fact, it was a pre-work because I was at Swedish in Seattle. And again, to stress no two centers have the same rules they all have different things. You know, I was told that I had to be within one hour of the transplant center for the first month. Unfortunately, I am within an hour anyway. But they've said I would have had to have found hotel accommodation near that if I was further away.

So, yes, it is. And I'll tell you why. It's important and this is something that nobody considers. But as we're amongst friends here, I'll share it. One thing that you never take into account is that when you're sort of going through reduced kidney function, your bladder size shrinks. And then when you've had a transplant, all of a sudden, your bladder is being filled with urine from your newly transplant, transplanted kidney and you trust me, you need to be close to the Transplant Center, an hour's journey for me was pretty tough going in terms of needing to, you know, not just empty my bladder sorry to be blunt about this, but you get were on camera.

Not only that, because the other point that Janet made was critical one is you have to measure the volume of the urine. So, you have to be in a position to not only get rid of the urine, but you have to be able to measure it to record it in your findings as well. So, being close to the appointment center is critical because your bladder won't be used to the volume of urine it's dealing with so quickly after the transplant.

Janet Gitterman: Yeah, I think I saw someone else What if you're not close to your transplant center? And they probably would want you to find accommodations for at least the first six weeks. They will tell you what you need to do.

Wayne Smith: Guys, it varies by center. It was a month as for Swedish but yeah, some I'm sure we'll be up to because those appointments are, as Janet says very, very regular. You know, you're there a lot, to begin with. And boy, do you give a lot of blood.

Janet Gitterman: Still.

Wayne Smith: Any more questions in the chat and feel free. Not sharing anymore. Okay, in which case well extend my thanks to you, Janet, for sharing. Oh, hang on. So, what can you talk about the pills? Yes.

Janet Gitterman: You're talking about the anti-rejection pills? Yeah.

Wayne Smith: The monkeypokes, the monkeypokes.

Janet Gitterman: I have one too. Except mine is a little smaller. I'm only taking mine at the morning and at bedtime. But I'm on a tacrolimus cell set. And oh, back to like that prednisone thing that I was trying to avoid. They put me on five milligrams. And just about a month ago, I talked my way into getting that halved. So, now it's only 2.5 milligrams. So, I'll wait a little while and then try again to get off it.

Wayne Smith: Kathy raised a great point in the chatter about needing to be near that there are lots of options, there are charities that help provide local accommodations. He's just in Ronald McDonald Houses. That's a great one. And again, these are all things that your transplant center in your code notice, and the social workers that the centers will be able to help you with that, certainly in my circumstances, and I'm sure Janet will concur that they really do everything to set you up for success.

They cover all the angles, sometimes in excruciating detail that you think is overkill, but believe me it's for a good reason. You know, they want it to be successful you know, both of you and Janet is paid for her dinner as well. So, you'll be taken care of, and they'll make sure they cover all bases with financial aid if necessary. Yeah.

All right. We're closing time now shots. I think I can see no more questions at the moment. Thank you, Janet, for sharing your experience it's been great I appreciate you for joining the session.

## Recovery from Transplant Surgery: A Patient's Perspective

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