Welcome to PKD Chronicles, navigating life with polycystic kidney disease.

A podcast by the PKD Foundation presented generously by Otsuka Pharmaceuticals.

This podcast is all about helping you live your best life with PKD. In each

episode, we'll explore the stories, science, and support and resources for families

impacted by PKD. And here's your host, Alyssa Ealy.

>> Hello and welcome. We have two very special guests joining us today to speak with

us about the patient experience of young people living with ADPKD. I'd like to take

a moment to introduce Sherita Turrell and Greg Minolfi. Welcome to you both.

- Hello, hello, thank you for having me.

- Really great to be invited on the podcast. Get some good conversation going.

- Excellent. I'm so happy to have you both here today. And I'm personally really excited to hear more about your journey with PKD, your experience navigating the emotional aspects of the diagnosis. Before we get started, why don't we take a moment for you to both introduce yourselves to our listeners.

- Yes, well, hello everyone. My name is Sherita Terrell. I have PKD. Been having it for some time was diagnosed when I was 21 years old and actually this year at 34 years old I got a transplant. So yeah that's just really my story a lot in between but yeah that's me from St. Paul Minnesota. Yeah who else do we have on today?

>> And yeah hi I'm Greg Monolfi. I'm a 30 year old out of Baltimore,

Maryland. I have ADPKD, at this point showing pretty minimal symptoms,

but my diagnosis was when I was in utero, so by ultrasound, so I've kind of known

about my PKD my whole life. A little different perspective than most of the

diagnoses, but I work as a transplant coordinator at Infinite Legacy an OPO,

an organ procurement organization covering the Maryland, Maryland, DC, and Northern

Virginia areas. I've also just been very involved in the PKD space over the past 12

years now. My mother and I both have PKD. So after her transplant about 12 years

ago, we decided to really lean into getting involved and kind of giving back to

this community that supported us. So really happy to just put my efforts out there

and make a difference however I can.

>> I can already tell we're going to have some great conversations. We have some really differing perspectives and then also some really interesting insight into transplant from multiple angles available today. So really looking forward to this conversation. So Greg, obviously, as if you were diagnosed in utero, you don't really remember what life was like pre -diagnosis. But Sherita, can you tell a little bit about or share with the crowd a little bit

about how he felt when you first found out about your diagnosis and how it kind of

affected your life in general?

>> Absolutely I would say before finding out my diagnosis my life was great you know just about you know anyone else had a great upbringing went to college did all the things lots of traveling but when I actually found out I was diagnosed it was a lot. I would say that morning, I do remember it like it was yesterday, I was headed into my first, of course, corporate job outside of college, had it going on, right? Brand new car, had my condo, I was living that life and actually collapsed on my floor and it was because of a cyst bursting actually. So I was in the hospital for about two weeks and my life changed tremendously went from no medication, of course, living my life, eating whatever I wanted, to then being in the hospital for almost two weeks, all these medications, schedules, family being

concerned, constant calls, you know, so it was totally different. And then at the end of the day, I learned so much and I'm happy to be able to share. So I'm grateful for the experience.

>> Wow, that seems like a really kind of a crash course into life with PKD for you

>> It took some time though I would say because after I was diagnosed under medications

for like a good six months, depression really kicked in so from there. I was like,

okay, I'm 21 years old. This is not my life It can't be as serious as they say

so I was skipping some days of medication Of course going out to Miami Memorial

weekend taking only one day of medication, leaving the others at home, not really

knowing how serious it was. Embarrassed to say though, but 21 years old,

you're like, oh, I'll take the medication, it's fine. You know, I was getting a lot

of headaches. So I think that was the main reason why I was taking my medication

when I did. Not knowing that was connected to high blood pressure. But yeah,

absolutely right. It was a lot, especially for a 21 year old. I was happy I was

21 and maybe not 13, you know, but at 21, yeah, I didn't want to embrace nothing

that I had going on as far as health wise.

>> Yeah, it's really hard to go from being healthy to all of a sudden having something that is kind of the center of your life and you have to kind of face it head on, especially at that age, you're kind of trying to find your way in the world.

>> Absolutely. You're so right. Being out of your parents' house, you know, making a little bit of money. It's like, uh-uh.

>> Definitely a change in lifestyle for you. So the emotional aspects of that must

have really been huge for you. I know you mentioned you were very depressed after

for a short time. Could you talk a little bit about what that was like for you?

>> It was, I'm always going to say it's a lot because that's the first thing that

just comes to mind when I try to express it all. But yeah, depression, it was, it

was a bit much because there was no one around me that could relate, right? And

then from the outside, you know, with just social media, my friends, group, co

-workers, all of them just think your life is perfect or close to it, you know? And

so I was in a way, I would say live in totally two different lives where at home,

I was dealing with, you know, my personal things. But outside of that, I was

totally dealing with just normal 21 year old stuff, just hanging out, doing all the

things. But at home, it was totally different. So spent a lot of time alone, not

really telling the truth to my family about how I felt, not telling the truth fully

to the doctors about how I felt. I felt like no one knew what I was going

through, you know? So it was a lot of hiding, if I could say. So I think that

made the depression even worse 'cause then after a while, it started seeping out and

my personality and my energy, how I was reacting with family and friends. Attitude,

energy was just totally off. So eventually I had to be totally honest. They knew

exactly what was going on, you know? But yeah, as far as just being depressed, I

would say a lot of times this crying all night, it was a lot to say the least.

Like days when I'm like, okay, I don't even want to shower. I'm upset with God. I

am literally done, you know? So yeah, it was, it was a lot,

but I would say dialysis was even worse. And I know we'll get to that, but that

experience, that depression, that was like, I'll jump off a bridge right now. You

know what I mean? So yeah, that was a little depression, but not to where it was

last year. You know?

>> Yeah. And where did you turn to for some of those sources of

support? You said social media, friend groups. How did you kind of embrace that

support system that was out there for you? Did somebody kind of lead the way for

you?

>> At that time, I really didn't. At 21, 22, 23 years old, I was kind of

dealing with myself. I was still going to church, you know, listening to worship

music, praying and all that. But being totally honest, I really didn't lean on

anyone else. I didn't really believe that they could understand me, nor that I think

I was at that time wise enough to know that my emotions and my story can be

trusted with certain people. So at that time, I really, I had definitely had people

that I could lean on, but I didn't choose to do so.

>> Yeah, it can be really isolating when you have something going on that people can't see.

And so I really appreciate that kind of hiding factor that you're talking about

because you don't wanna be forthcoming with everybody you come across and say,

"Hey, I have this thing going on." But it's also a lot to hold that in. So

looking back, is there anything that you wish you had done kind of differently? Is

there anything you wish somebody had told you to kind of help you feel like you

could navigate those feelings with a little bit more of a larger support system?

>> Yeah, I feel like I know for a fact and wish I would have been more honest. And

also knew that it was okay for me basically to say quote, unquote, let my hair

down. Like I don't have to be perfect. I don't have to be what everybody assumes I

am based off of a picture or them just seeing me in passing, you know? So I wish I would

have been more honest with friends, family, especially at the doctor's office, I also

wish I would have maybe gotten to some type of therapy. But a lot of times, I

will say in the black culture, for sure, therapy is not really something we

discuss. You know, a lot of things that happen kind of stay at home. Everyone's

judging you. We're always on the news, the list goes on and on and on. You know, so as

far as looking perfect in church and the community, not really letting our personal

business, family business, health, anything like that, just kind of be out in the open.

But looking back, I know for a fact, this whole thing could have been way smoother,

less stressful, if I would have been completely honest with everybody that was in my

circle, which I totally am now, you know? So it's like, if they would have known

earlier, I think everything just would have been different. But I know that all

stems from me just having this off kind of confidence and kind of assuming that I

have to have it together. Because none of us do, right? Especially at 21 years old.

So I wish that would have been something that I would have done earlier.

Just trusting people, connecting with people, being more open, not being afraid, for

sure.

>> Yeah. Definitely easier said than done, Sharita. So I think that insight that

you have into this now is just incredible. You've really learned a lot over the

past several years. So very impressive. And those feelings that you have worked

through are huge. And it's just incredible that you have grown so much through this

experience. So I would say I'm really proud to hear that you have just accomplished

so much.

>> I really appreciate that.

>> Yeah, excellent. Thank you so much for sharing

that story. Greg, I think your story's a little bit different, a different

perspective. So could you share with us a little bit about your experience as a

young person living with PKD your entire life? So what was that like when you were

younger, living with PKD? How did it affect everything that was going on in your

life?

>> So I know that probably for the fluidity of the conversation.

It'd be great to answer that question you just asked me, but I don't think I can

just pick right up without acknowledging the story that I just heard from Sharita.

I mean, Sharita and I were able to connect before this podcast session and she was

able to go into a lot of these details of her story, but I'm sitting here on

mute, I cut in the audio record, but you're swelling my heart here.

>> I'm about to cry too. That's crazy. To be honest.

>> So I know that one of the comments I wanted to make there is it's perhaps one of

the most devious part of our disease, our polycystic kidney disease, is that it is

not visible. It's a nice feature that you can disguise it, you can hide it,

you can move along without needing to acknowledge it, but it's certainly doing more

harm than good to us, I think. By not needing to face it, we tend to seek avoidance. We tend to avoid it. And that's human nature. I mean, life is complicated. there's a thousand things going on. The last thing you want to do is the most adult thing possible, which is

acknowledge the full extent of your lifespan and how your health will look in 30

years. But I'm just, I'm sorry that you had to go through that the hard way.

I don't know, I just have to acknowledge and thank you for sharing that, Sharita.

>> Well, thank you. If I didn't go through it, I wouldn't have met you, right?

>> Hey, now, that's, let's, so we're gonna build on that. We're gonna build on this message

that I'm gonna be, that I've been preaching since I started my involvement in the

space of how can we draw positivity from this otherwise entirely negative situation?

I'll come back to this point later. I'll definitely give you the full picture of my

master thesis that I've been working on for PKD.

>> I would say totally fine to continue with this train of thought. Like if you have it there, I'd say just go with it.

>> Ha ha. For context, okay, we've got my story.

So, you know, I mentioned being diagnosed in utero. My mother and I were essentially

diagnosed at the same time. I mean, my mother was completely unaware of her kidney

disease until, you know, going through those tests when I was in the womb.

So having, you know, I can't speak from my mom's experience necessarily, but I have

to imagine going into that doctor's appointment to get a checkup on your little baby

and to see this, these cysts on their kidneys. Oh my God, what's going on?

And now to then move the wand of that ultrasound over and see her kidneys have

these cysts as well. And that moment of an entire world turning upside down.

Not only are you having to deal with this new issue, your baby is now having to

fight a fight you didn't even know you were having to go up against. So I really,

I cannot tell you how my parents sat me down and told me about my diagnosis.

I think they slipped it in there. You know, I think growing up that just kind of

was mentioned and incorporated in, it was very normalized from a young age for me.

One of my, a fond memory I have with my grandparents is sitting at the table in the

when I would visit them. And my grandparents, of course, they have like eight, nine,

ten medications that they're taking vitamins and pills. And I kind of wanted to be

a part of the fun. So I got my Flintstones gummies and my Flintstones vitamins.

And they would practice, they would teach me how to take pills, how to swallow your

pills. So, you know, that I think that's so weird. When I told it to someone,

when I've told other people when I was growing up that that's something I was

skilled at taking pills. It was like, what the heck kid? But I started taking blood

pressure medication at age 11, I think age 11 or 12. Already my blood pressure was

starting to be dysregulated. So I've been taking Lysinopril more than half my life

at this point. But that's just kind of been incorporated into It's just been

normalized from a young age. I think that I didn't understand PKD I didn't

understand how significant would be until my mother started showing more symptoms.

So my mother at age 47, 48 got to that point of end stage renal disease needing to

go to the doctor much more often needing to get these supplementary treatments until

she eventually transitioned to dialysis. And as we've mentioned before a little bit

here, or as we'll speak more on behalf of, dialysis is tough stuff.

So I think PKD became real for me when I saw it affect my mother. And I'll admit it to this audience. I'm a mama's boy. All right, I'll say it. I'm an only child. I love my mother. She's my home. She's my heart. And to, to see her, to kind of degrade, to break down, to have the energy zapped from her through this process was, was, was tough. Trying to support her the best I could. You know, I'm in high school at this point, helping out, making the meat, helping cook the dinners, helping to take care of the chores around the house. But I didn't allow myself to be afraid. I didn't allow myself to be sad or mad or angry because I had to push that down and focus on my mom.

So I've got an incredible talent for compartmentalization of my emotions. So my story is more of how well can I deny? How well can I hide or store away any of these negative emotions? I thought that these negative emotions were not productive, that they would not serve me, and therefore I was going to trim the fat. If I don't feel mad, sad, angry, then everything's going to be good, but clearly that is a, that's how you make a ticking time bomb. That's how you pressurize, that's how you build pressure that will one day need to unleash.

So, you know, all was well eventually. My mom did eventually go through her couple

of years of dialysis, with no success finding a living donor, spending time on

that transplant list, getting an occasional phone call in the middle of the night.

Can you come in? Can you make it? No, maybe that's not the right one. Some near

misses. In truth, eventually, I'll stay broad. Eventually, through a paired exchange,

my father, my hero, my father, was able to give his kidney to someone and their

spouse matched my mother. And so they did a paired exchange. So, two living donors,

two recipients. It happened a couple months apart, so I'm literally finishing.

I graduated high school, my mom gets a transplant, and on my move -in day for

college, my dad's getting a surgery for his kidney to be removed to donate his

kidney. So again, a transitional time, you're growing up, you're moving, and you're seeing this all happen, but that's the success, that's the good part of the story. So we made it through the tough times. It got real there for a while. We made it 12 years now. My mom's been happily, healthily living her life. My father is perfectly fine as well. So it's a happy

story for now, but that experience of going through that dialysis of going through

that diagnosis. And again, as Sharita mentioned, not really having anyone else that

understood what we were going through. PKD is one of the most common rare genetic

diseases, and yet it is so isolating because of the lack of participation from our

community, the lack of acknowledgement, the lack of diagnosis of what we're up

against. So one of the most formative experiences for me after going through this

process, the person you see here today was made from attending the PKD convention in

2014 in Kansas City. So for the first time, I was able to meet someone that had

PKD that was not me or my mom. And a whole conference of people,

hundreds of people that were all there because they were patients, they were

caregivers, they were scientists, they were doctors. This amalgamation of these

different partner teams all together, it blew my mind. I never received such

acknowledgment, such validation for the disease that I thus far thought was isolating

was not only my problem that no one cared about.

So from there, I knew that I had to get involved. I knew that I could channel my

angst, my worry, my sadness, I knew where to put it. I knew I could channel that

into something productive. So I think that from those experiences,

I started down this path of getting more progressively involved with the PKD

Foundation, with talking to patients, with normalizing my own disease, with

acknowledging that by receiving that validation, I was able to embrace my diagnosis

more. I was able to not be Greg, and on the side or behind closed doors,

a PKD patient, I was able to merge those two and step out into the light and kind

of forge a new path using PKD as an empowering element of my story,

of my personality.

>> Wow, these are both just such incredible stories.

I wish I could tell you what it means to me that you guys shared this with our

PKD community. It's just incredible. And I think it's so important.

The message that both of you are sharing is that these are, this is something that

has been isolating through your formative years when you should be out living life

like a kid, like a young adult. And I think if what I'm hearing,

if what I'm hearing is correct, is that both of you really encourage other young

people to get out and get involved in this PKD community and find those people who

can support so that they too don't have to go through this isolating process.

>> Oh,

Greg actually sent me an email with some information on how it could be more

involved, so I want to take a moment to thank you. And I really hope next year

I'll be at that conference who can actually meet in person. How nice would that be?

But thank you, 'cause I do wanna get more involved myself. That is actually a huge

goal of mine. I actually just got a nonprofit, a 501 (c)(3) called Make A Difference Kidney

Foundation. So I am now four months in after transplant. So I really wanna get

involved. Now that my emotions and all of that is in alignment,

you know what I mean? So I feel like I have that space to learn more, embrace,

share my story. So thank you for sending me that email. I definitely read it and

I'll be reaching out to those people. So thank you. And then one more thing too. I

know they're gonna chop this up a little bit. But I did want to you started taking

high blood pressure medication at 11 years old, right?

>> Yeah, that's right.

>> That is wild to me.

And it's crazy as I just think about, think back on my experience. I was like, I

should have started high blood pressure medication between nine and 11. My parents would take me to the doctors all the time 'cause I would miss so much school. I would

have these terrible migraines. I mean, couldn't open my eyes. I would puke all day. My head would be pounding. Like I would have to have ice on my feet on my head. I would go to the doctors. “Get on birth control. You need birth control. Your estrogen is high. You need birth control, birth control.” I'm like, I'm going to lose my mind. What do I need to get on birth control for, for these headaches? Why isn't there any more research being done? Why

did they keep pressing birth control? But they kept saying the headaches were because

of my estrogen levels being high. And then finally, after all this experience before

starting dialysis, I don't know if I can say this. You can x it out or click it

out. But yeah, I was going to have partners. And I was like, you know what? I

just want to go back and look at some of my records. And I've been having high

blood pressure since I can—believe it like since I was in junior high,

like 130s plus, you know, so it started way back at 10, 11 years old when I was

missing school every day because of these headaches. And a lot of times, I think at

that age, they always relate blood pressure back to anything. Not blood pressure,

excuse me, birth control at that time, I don't know what it was. But even in high

school, I remember birth control was supposed to be the answer to everything. And

I'm like, what the heck is going on? And then for me to find out at 21, my blood

pressure was like 190. I'm like, what the heck is going on? Because my blood pressure had

been high. But I was, no excuse, but it was like, I was too young to really pay

attention to that. I think also my parents were listening to the doctors and were

like, oh, you should just get on some birth control. You just started your period. That's

why you're having all these things. And I really think it really had everything to

do with PKD and having hypertension. And it just blows my mind where it's like I

didn't I don't know anybody that's taken medication that young but I just think back

like man that maybe was what was going on with me I think that's what was going

on with me you know now that I think about it so I just wanted to point that

out that gosh 11 years old that's what you were doing and I honestly think I

should have been doing the same so yeah just want to point that out.

>> No that is a fantastic story and I actually think that it has a lot of value to it.

I remember those days where they just basically like birth control was the answer to

everything like 15 years ago. I don't know why that is. And I think it also speaks

to the fact that you guys and your stories are so important for other young people

who are going through now, what you were going through then. Like advocating for

yourself, getting involved in the community, speaking up, it's like as Greg mentioned,

it is a rare disease, but it's a common rare disease. And so there are a lot of

people out there who don't know where to find these answers. And for as many people

that are out there that don't know that they have PKD or are newly diagnosed and

don't know the right steps. There's so many providers out there who still don't know

a lot about PKD. And sometimes the patient really needs to fight for themselves and

say, "Nope, you need to treat me. You need to look at bigger things."

>> Yeah, I think that we perceive our medical system as very advanced. And I believe it is in many ways, but it fails to connect the dots. And when you're facing a diagnosis of

chronic disease like this, you can't trust that it's going to all come together

without putting in that effort. So I mean, from my side, even though I was on

those medications, my mom almost didn't believe that I needed medications that young.

She thought, “oh, you know, well, now you're getting into running, you're more active,

maybe your blood pressure will go down, you don't have to take those medicines.” But,

you know, so I stopped the medication for about a year, but I came back to the

doctor, they said, "What are you doing? "Get back on those." No, no, no, we gotta,

it's, you know, you'll go to the doctor especially, they say, "Oh, your blood

pressure is low, maybe you're just nervous." Well, that's, that's, we can't trust

that, that if you think that you have a chronic disease, if you think especially

that you've got PKD in your family, you really have to be vigilant about your blood

pressure. The number two cause of kidney failure in the United States is high blood

pressure, behind diabetes. The number four cause is PKD, but maybe there's a

combining factor there, obviously. So just any time that you can regulate your blood

pressure alone is going to, I have to imagine, save you weeks, months, years on the

lifespan of your kidney. So I really, you know, the idea that you'll deal with your

PKD when it becomes a problem is flawed because it's already a problem.

It's a small problem that's only growing bigger. And though you may not see any

difference for years and years and years, there are progressive changes going on in

your body that you cannot feel, you cannot see, you cannot detect with a simple

blood test. And so I think that there's, it's very important to at least be

prepared, at least be cognizant of what's happening from an early stage.

And I know that I don't know and I don't know that I don't understand what it's

like to not know if you're diagnosed or not. I have always known about my PKD so

I really don't know what the thought process is behind having family diagnosis and

considering if you should get tested or not. That's a whole different situation. I've

never been in that, but speaking from someone that's always known about it that's

had time to mature, to grow, to normalize my diagnosis, I think it's going to

vastly improve my health, my mental capacity to handle the things that come next,

and to just be a part of this community. I think that delaying that diagnosis is

not serving your needs. I feel it is the easy way out.

But I think that by delaying that diagnosis, you're pushing off a lot of the

difficulty that you will have to eventually go through.

>> I agree.

And let me just say I want to meet your mom one day. She did an excellent job. I

am so happy that she was honest until the beginning, 'cause I know you guys are both learning together in a lot of ways. So that's absolutely beautiful. And even her experience when you were talking about her and going to get an ultrasound, like I can relate in so many ways. And it just makes me, of course it makes me get emotional again, 'cause I am a

Scorpio, we get emotional, okay. But it just makes me think like I connect to her

so much. So it's like, I would love to meet her and talk to her and see how

she got through that. That just blows me away. I literally go to OB /GYN,

happy news, get an ultrasound, and then you find out you have this disease that

your child does. So it's like, I can imagine how she felt, just thinking like,

"Wow, I'm now putting this onto my child who has to grow up and deal with what

I'm dealing with." I know she probably was just like, you know, she probably had a

million and one thoughts. You know, you're such a small child, medication early and

all the things, but she did an amazing job with you. And I'm so happy for you and

for the both of you and even your father being healthy and you learning all the

great things and sharing. It's beautiful.

>> Yeah. I agree. I love that story about the Flintstone vitamin. I like normalizing the pills because I know plenty of adults who would need a hand with remembering to take their pills. So I think the fact that you had it normalized into you as a prepubescent child is incredible.

>> That's a funny one.

>> I think one of the things that's really incredible is that you

both have taken your unique experiences with dialysis, with transplantation,

and Sharita, you mentioned you have a program that you've started and Greg, you work

in transplant. You're giving back to the community that you come from, so can we

take some time to kind of hear more about these two experiences as well?

>> Yeah,

well, I'm just actually getting started. My husband and I, so we started the

foundation, the Make a Difference Kidney Foundation, and we're actually having our second annual kickball event. We're now kind of added that on to the foundation.

And I actually just got an email today that my coordinator from HCMC, new name

Hennepin County Medical Center, she's actually gonna speak. So I was like, oh my

gosh, that's so amazing. It literally brightened my day before hopping on this

podcast. But I live in the Rondeau neighborhood, St. Paul, Minnesota. You can go

online hear all about it, how our bridge 94 went through the black community. We're

just trying to figure all this out from back in the 80s. But I live right in the

neighborhood, in the city, and even the dialysis center I went to is about three,

four blocks away by our capital. And so after going to dialysis, also working health

care, after going to dialysis, being around the neighborhood, and actually sharing my

story. So my father is the one who kind of put my story out there, got it in the

news. My husband and I were talking and we're like, we need to actually create something.

We need to share our story as he actually donated his kidney to me in March. So,

super grateful and blessed to have him in my life. Can't even believe, I know,

couldn't believe in 2008 when we met that he'll be my husband and also he'll be my

kidney donor in 2024, wild. But without that being said, before I keep rambling,

We thought it would be a great idea to start a foundation, to just share the

information, all that I know, all that I'm learning, and create different programs,

fun things to do, also speak, which I'm working on my speaking, but working on some

speaking engagements in the next few months. So that's what we're doing, it's all

brand new, of course, it's a journey, learning, connecting with different people, and

still trying to fit that in my schedule of starting to work back full time, also

still going to the doctors twice a week, but that is our plan. Just to get the

word out there, the education out there, letting people know that all things are

possible, right? And even letting people that look like me know that a lot of times

after you even donate, your life, God knows, but most of the people, they just

continue having a great life. I'm a husband, as a tennis player. Literally 12 weeks

went by, He's doing his jam. He's going to nationals in November. You know what I

mean? So, it's just like a lot of our people just don't know that you'll be okay

after it and there's purpose behind it and so many great things can come from it. It's

just like, donate a kidney? My kidney? What's going on? You know, that's

how they feel. Or they even think you have kidney disease that just basically gonna

go to dialysis. You're gonna look terrible and you're gonna die. Like no, greater

can come from that experience. You can still have a great life. Your life can

probably even be better. At least I know mine's is, you know? So just getting that

information out there and letting people know like your life is not over, you know?

So that's really the goal. Just to let people know that all things will work

together for the good, okay?

>> Absolutely, that's amazing.

>> All right, you want a lightning round? I got some stuff to say.

>> Excellent.

>> Okay, so you asked about, you know, the end result, the how at this stage we've been able to get more involved.

Like what has been our motivating factor? How have you see us today at this,

you know, evolved stage of self -awareness, of involvement, but this didn't happen

overnight. I think that from my perspective, I really like doing things efficiently.

I like to do things that have the most impact with probably the least amount of

time and effort that I have to put in. So I think one of the best ways to get

involved in this space is taking baby steps. What are little things that you can do

to start to get the ball rolling and get yourself comfortable with being involved

with the PKD space? So I showed an interest in biology. So I was talking to my

PKD specialist. She asked if I'd like to visit the lab, like to tour their lab.

Amazing. Absolutely. Let's go see what kind of research is happening in a facility

like that. I ended up shadowing for a summer, for two summers now, and participating

in some of that research as doing bench science for PKD.

And that was, again, Incredible for a biology minded person for myself. But that's

something that I used to build on. I took my experiences from the PKD conference

and kind of how connecting with others made me feel good.

How can I get that good feeling? How can I give back? How can I connect with more

people? Because clearly that's doing something right. I think one of the main

mindsets that I've been able to take on recently is how can I interact with my PKD

productively? I think there's a lot of unproductive things you can do with regard to

your PKD diagnosis, but what can I do productively? How can I engage with my PKD

at this stage that's going to bring about a benefit? You know, as I said, I'm 30,

my GFR is looking great. I got a couple aches and pains here and there, you know,

a ruptured cyst or two, but for now I can take my medicine, I can diet and

exercise, but I've just got to wait around. But what can I do to engage

productively? So I would say that what kind of small opportunities are there that

can warm you up to bigger opportunities. So simple conversations with strangers on a

bus or, you know, talking to your family, educating others, just even saying the

words out loud to somebody else to say, "Yes, I have PKD. Let me tell you a

little bit about it." It's very, it takes a lot of effort to be that vulnerable,

but the more you do it, the more practice you get with it, the more normal it

feels. And I've got a friend right now who is actively looking for a kidney transplant

and she's doing so good at growing and being able to tell her story and being able

to ask those questions and I just love to see her progress. I'm tracking her story.

I'm really hopeful that she'll have a good outcome here, but it takes practice. This

doesn't happen overnight. These baby steps to enroll in some of the emails from the

Foundation, to get educational materials, to learn what research is happening, consider

joining a clinical trial, or even easier, you can register to be in the PKD

registry to fill out some surveys, to spend time thinking about what is going on in

your body. Of course, there's infinite number of volunteering opportunities. Joining

the Walk for PKD is I think one day of the year that you can go to a place,

meet other people, and be proud. And it can be normal to be a PKD patient by

going to the Walk for PKD across the country. So I really encourage anyone that has

PKD or PKD in their family to pick out their local walk and join that this year.

I mean, It's the best day of the year to have to have PKD,

but there's also a lot of advocacy opportunities. I'm involved in the Advocacy

Champions Network and being able to reach out to our political leaders and make them

acknowledge our diagnosis, make them acknowledge that their constituents have PKD,

that we are a large number of people that need their support in getting funding for

research in protecting the rights of patients that are on dialysis and to protect

the rights of those that are heroic enough to donate an organ. Those are some of

the major points I want to make.

>> I love this. I feel like we could talk about these topics forever. I have loved listening to the two of you. I'm sure our listeners will feel the same way. Are there any closing words that you want to share? What's next for you? Any words of wisdom that you want to share as your final thoughts before we wrap up?

>> I would just say I'm in a process of learning and growing and taking back all the

energy and other things the devil thought he took from me. So just be on the

lookout. I'm gonna do all the things I thought I couldn't do from maybe being in

another podcast, writing a book, my foundation being recognized next to the National

Kidney Foundation or the PKD Foundation. I feel like there's no limit at this point.

And so that's what you should be looking out for Sharita Terrell. And words

of wisdom? I would just say that if you have PKD, if you have dialysis, wait one

more day because there's days when I felt that way whereas I was like okay If I

could just get through this day tomorrow might be better and for a few days it

didn't get better But I just kept telling myself just the next day the next day

And eventually that happened for me And I believe it will happen for whomever it is

that's listening that's on dialysis or is waiting for a kidney transplant I know the

waiting list is no joke. Okay. I've been there done all the things But it's not

the end And if God literally woke you up, there's purpose in that day. Now I'm

gonna get emotional again, so I'm gonna stop there, but keep fighting.

>> Greg, any thoughts from you?

>> Yeah, so again, I think the biggest impact that we can have

with any listeners or the PKD community is hoping to reach these people that are in

the earlier stages of PKD. As I like to say, It takes fear to be brave, and so it requires you to be brave, to face your diagnosis, to look it in the eyes and take action now,

not wait until it becomes a problem. And I know that sounds really difficult, that's

a huge, monumental task, but There are little steps you can take today, being honest

with your doctor, being honest about your emotional state, talking to, activating your

inner circle. You have friends that are going to be there for you and to trust

them with your diagnosis. Trust them to be a safe space for you to start to

acknowledge the fact that that is what you have to deal with. I think my biggest

message is to find ways to harness the strength of this perceived weakness.

So PKD is often defined by what it takes from us, but I really try to flip the

script and ask, "What can PKD or what has PKD given me?" At this stage in my

life PKD has given me a community. It's given me a unique perspective on life, on

mortality. It's given me a passion to pursue. It's going to fuel research for future

generations. And that doesn't balance the scale, but those are small positives. These

are positives that you can find. And if you're able to find that little positive

speckle in an otherwise dark world. Then that's, I think,

one of the major reasons we're here. So, and keep going one day at a time, you

know, Sharita, it's gonna be okay. We're here for you.

>> And vice versa. Oh, my goodness. I love that. Take back all that PKD trying to take from you. You better go ahead with your bad self.

>> I know that was really inspirational. That was so amazing. I'm so sorry that we're out of time, you guys, because this has been so great, but I will say thank you so much for being here today. And thank you or all you do for the community for sharing your stories. They're so powerful. And I teared up a few times listening to the two of you talk, I think you've both

been on incredible journeys. Your work certainly isn't done. So I hope as we go out

in the world, you continue to be that change that the PKD community needs and

appreciates. And I hope those who are listening, learn from you, embrace all that's

out there, and listen to both of you. You both have some amazing words of wisdom

that you shared with the group today. So thank you so much for your genuine selves.

>> Thank you. So kind. I'm happy to be here. You're happy to meet you all.

>> And we're just getting warmed up, you know?

>> Amazing. Thank you so much to both of you.

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