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.

>> Welcome everybody. Today we're going to explore the unique challenges and

considerations faced by individuals with PKD in the family planning process. We are

joined today by Dr. Dallas Reed. Dr. Reed, welcome. Why don't you tell us a little

bit about yourself?

>> Thank you so much for the invitation. So like Alyssa said, my name is Dr. Dallas Reed. I am a OB/GYN and medical geneticist at Tufts Medical Center in Boston. I work as the division chief of genetics and the director of perinatal genetics there and also am an attending obstetrician.

>> Excellent.

So sounds like you have a lot of experience taking care of individuals who are in

the family planning process it. So how do you incorporate this into the care of

individuals with ADPKD?

- Yes, so my clinical roles are two. So I have two separate

offices in which I see these types of patients. It sort of starts from prior to

pregnancy. So my colleagues in nephrology will refer patients to me who have a

diagnosis, a clinical diagnosis of PKD. Oftentimes, they are interested in doing

genetic testing purely for reproductive reasons, and so I would see those patients in

my genetics clinic and do some pre -test genetic counseling around the genetic

testing, offer them that testing, and then when the results come back, share those

results with them. We often, at that time, have a discussion about what can you use

these results for, how can these be used in a reproductive way, and that discussion

starts even prior to doing the testing. And then they go on their way to do their

invitro fertilization and use those results for that. And then once they become

pregnant, I can see them back in my obstetrics clinic as a pregnant patient. And we

can work with our maternal fetal medicine colleagues to take the best care of them,

especially if the person with PKD is the pregnant person.

- So there are definitely

some differences for those who have PKD versus those who don't that will change the

way that they go about the family planning process. So what are some of those

considerations that people need to keep in mind as they are kind of entering these

family planning years of their life? How does that differ for patients who do have

the PKD? In addition to all the in vitro fertilization, how does this information

really change?

>> Yeah, so again, it starts all the way at the beginning even prior to

pregnancy with an understanding or a discussion between the couple about what their

goals are. So there are sort of two ways forward for people who have a known

genetic condition. One way is to do the IVF process, so do genetic testing on

embryos to decide which embryos do and do not have a genetic condition and use

those for pregnancy. And then the other route is to not do that and to conceive a

pregnancy naturally and either do genetic testing in the pregnancy or at some later

point. For people who are going the IVF route, a very important thing that's

different for them than maybe others that are going through IVF is that in order to

use the genetic testing to decide which embryos do and do not have the PKD genetic

mutation, the person with PKD, the person and the couple that has PKD has to do

genetic testing first. They also have to have a pathogenic or likely pathogenic

variant identified in order to use that for reproductive reasons. If they have a

variant of uncertain significance or no genetic finding, then there is not something to you know

available to use for genetic testing for the embryos. So that's a very important

piece. Another piece with IVF is that genetic testing often requires other people in

the family to get involved and so there might need to be the parents of the person

who has the PKD may also need to submit samples to help the genetic lab identify

the probes that they need to use on the embryos. So it's important to know it can

be an even more involved in process than it is for people who are using IVF for

other reasons. And so it's really important to start thinking about these things and

having these conversations way before you're ready to become pregnant because they do

take time and there may be lots of steps involved. In regards to the second group

of people who are choosing not to do IVF and want to get pregnant spontaneously,

if the pregnant person is the one with PKD, there are a lot of pregnancy

recommendations that we make and consultations that we recommend. And so those start, again, ideally prior to pregnancy. So having very good control of your kidneys and

blood pressure management prior to pregnancy, being on blood pressure medications that

are safe for pregnancy and stable on those medications, usually having a consultation

with a maternal fetal medicine specialist so they can talk to you about all of the

things that may need to be monitored or different about your pregnancy. And then

having an OB/GYN that has some familiarity with PKD that you feel comfortable with

helping to manage you and is able collaborate with your, your renal specialists are

very important pieces.

>> So when families are going through the family planning process,

are there differences in counseling for when the parents with PKD is assigned male

at birth versus female at birth and will or will not be carrying the fetus, does

that change your family planning and counseling approach?

>> So, yes, as far as the couple who's deciding to go the route of IVF,

it doesn't change so much because we still have the step that the genetic testing

needs to happen in the affected person before that can be used in the pregnancy.

Obviously, a lot of the preconception discussion is regarding pregnancy and management

of the pregnancy and management of the pregnant person to make sure that their

kidney disease doesn't worsen and that that kidney disease doesn't affect the

pregnancy. As far as the effects on the fetus, we know that PKD is a dominant condition. And so in people who may not have already done genetic testing of the embryos, we know there's a 50 % chance that the fetus could also have PKD. There can be features seen on ultrasound in the affected fetuses. So a small percentage of affected fetuses could have enlarged and echogenic fetal kidneys. And there can be complications for the fetus or newborn, especially if they're already symptomatic in the prenatal period after birth. But

other than that, there are not differences if the person who has the PKD is not

the pregnant person.

>> Excellent. So for those who may not find out that they have

PKD until they are pregnant, are there any differences in the outcomes for those

patients who have PKD versus those who don't, or do you find that it's pretty

consistent across the board with adequate and comprehensive health care?

>> So I don't have statistics on differences in outcomes in people who are diagnosed with PKD in pregnancy versus ones who are already aware or ones who don't have it at all. But

we do know that the outcomes in pregnancy really depend on your kidney function and

the control of your hypertension. So those are the two pieces that if it is

diagnosed in pregnancy and their hypertension is not well controlled, you know, there

can be risks to the pregnancy and risks to the pregnant person and same with the

kidneys, you know, so we want to, we obviously at that point would develop a

multidisciplinary team that includes the renal folks, high risk obstetrics, as well as

maybe their regular obstetrician to be able to give the best, most comprehensive care

as you, as you mentioned.

>> So once an individual is actually pregnant, are there any other special considerations for PKD. You mentioned including an interdisciplinary team, hypertension management. Is there anything else in particular that an individual would need to look out for during pregnancy that may be different from a general population without PKD?

>> So the biggest concern with renal diseases and hypertension is the development of preeclampsia later in pregnancy. Pre-eclampsia is out there a little bit in in lay media, but pre -eclampsia is the development of high blood pressures or higher blood pressures than baseline at the end of pregnancy as well as proteinuria or more proteinuria than baseline and other lab abnormalities. This can this usually happens in the third trimester, but in severe cases can present in the second trimester and Preeclampsia comes before eclampsia if it's not treated, and eclampsia is all of those things I mentioned with the development of seizures. And so that is one of the big health risks that we are monitoring for and concerned about in pregnancy. In order to monitor for that, we usually wanna get

some baseline understanding of what someone's blood pressures are, renal function is,

we check their kidney function, blood counts, things like that to know where they're

starting because it can be very confusing if we only check later on and those

things are abnormal. In people with PKD who are pregnant, we expect that they might

have some proteinuria, right? We expect that they may have an elevated blood

pressure and so we don't want that picture to be confused later on. The development

of preeclampsia and pregnancy requires us to often deliver patients earlier than we

expect based on a spontaneous labor. It also may mean that we need to have a

closer watch on their blood pressures and change medications or increase doses. And

we also would want to do some surveillance of the fetus as the pregnancy goes on,

checking the growth and other well-being for the fetus. One of the things that we

can do at the beginning of pregnancy besides doing these baseline labs is to start

the pregnant person on aspirin, 81 milligram aspirin has been shown to decrease the

risk of developing an early onset preeclampsia that can result in like a preterm

birth in people who start that in the first trimester. So usually by 12, at 12

weeks is when we want to start that medication to help reduce that the risk of

developing preeclampsia, and they continue that until they deliver, and that does seem

to be helpful.

- With all of this conversation about needing an interdisciplinary team, there's a lot of pieces involved in planning pregnancy for a family that's affected by PKD. So what are some of these resources that are available for individuals? Is it best to be set up with a Center of Excellence, so the PKD foundation, can a general obstetrician and gynecologist manage some of this? And where should people really seek out some of this extra support that they'll need along this process?

>> So if those things are available to you, especially those PKD

centers of excellence, that is obviously sort of the best way to start your journey.

But that is they're not everywhere and they're not stressed out across the country

in a very sort of even way. And so that might not be available to you,

but that's okay. I would expect that a physician, an obstetrician who is not near a

center of excellence should have maternal fetal medicine colleagues that they do

collaborate with because even low risk pregnancies can start out low risk and become

high risk. And so those specialists need to be available. Those types of

consultations can happen from between the physician to physician so it it may not be

that the pregnant person needs to meet or the soon-to-be pregnant person or a

couple needs to meet with the maternal field medicine specialist but there should be

a conversation about what are the things that the obstetrician needs to look out for

and what are the possible risks and how are you going to manage the pregnancy going

forward? So that would be, I think, the best way to approach the pregnancy. When

you're thinking of the genetic side of things, again, geneticists and genetic

counselors are not always everywhere, but genetic counselors are often affiliated with

maternal fetal medicine specialists. And so that's also a good resource. And then,

of course, the PKD Foundation has a lot of information and other families who are

going through what you're going through and are always an excellent source of

information for patients, whether it's before, during, or after a pregnancy.

- All right, excellent, thank you. If you had to guess, what do you think is the most

often asked question or most commonly asked question from patients to you that we

haven't already discussed today? Like what are some of the things that come to you

from the patient perspective, and what are they concerned about when they come and

talk to you?

- You know, I think one thing that's important to keep in mind, which we think about anytime, we have patients with a genetic condition, especially an adult onset genetic condition, is that the opinions vary amongst the population of people that have that genetic condition, about if they want to know or not know if their child could have this condition. So, you know, we're always dealing with two people. We're dealing with the parent who has the condition and then the potential offspring. And so I definitely had, you know, I think a lot of times the discussion is around, how will I know if my child could have this? How could I potentially prevent having children with this condition? But there are people who don't want to do that. And they also don't want to know because they want their child to be able

to have like a normal childhood and be able to, you know, get good care as they

become adults, but be able to have some autonomy over their decision about knowing

about that. And so one, I think doctors should know, they shouldn't assume, this is

true that a lot of genetic conditions, but they shouldn't assume that a couple wants

to prevent this type of a genetic condition from happening the other thing is it

can be tricky because there are some fetuses with dominant PKD that have symptoms of

kidney differences on prenatal ultrasound and Physicians and maternal fetal medicine

specialists are not in the habit of not sharing what they see. And so it could be

the case that you are someone that doesn't necessarily wanna know, you aren't going

to do testing during the pregnancy, you aren't going to test your child later on,

but we may find things on ultrasound that make us suspicious that the fetus has

PKD. And those will be shared with you. We will not not share those things. And so

it's important to just, I think, understand that there's a spectrum of feelings, a

spectrum of how people want to process this information, how people want to build

their family, and none of us can assume what anyone's thoughts or feelings are,

and so it's really important to ask those questions, but on the patient side it's

important to know, even if you don't want to know, there may be clues, there may

be things that lead us to being suspicious that the fetus could have the condition.

>> Okay, and so if a patient does not want to know, are they able to tell their

provider that they don't want to be told about those clues specifically? Is that a

conversation that they can have early on in pregnancy, or is this something that is

really going to be shared no matter what because of medical practice?

>> I think it's very challenging to see a difference on a fetal ultrasound and not

share that with the couple.

>> Right.

>> Because there may need to be follow-up tests recommended

or follow -up ultrasounds recommended, and so it makes it very challenging to have a

discussion about the fact that, you know, we did your ultrasound, we're going to

need you to come back in four weeks we're going to need to do another ultrasound

and sort of not talk about why that's happening. There also can be the situation

where one of the parents has PKD, the child has a renal difference on ultrasound,

but it's not due to PKD. Maybe it's due to something else.

>> Right.

Maybe it's another genetic condition. And so we can't also assume, unless we do testing,

we can't assume that it is the same thing and therefore, since they don't want to

know, we can't talk about it. So, you know, I think it's a conversation to have

with your doctor. I think that most people, most physicians would find it very

challenging to not share what they see because there's not automatically just one

assumption about what that thing means.

>> Absolutely it's definitely a time where there needs to be a lot of open communication on both sides so definitely makes sense that you have to share. So thank you for clarifying that I'm sure it's it's a tough time for a lot of families because you want to do everything you can to protect your fetus but you also want to kind of manage this chronic condition that

you've had on your own as well so there's a lot of pieces to it. I'm sure there's

a lot of emotions that are beyond routine pregnancy. So one of the questions that

comes up a lot in my practice is with the adult population with PKD is actually

not so much from those individuals who are of childbearing age,

but those who are parents of children, adult children who are of childbearing age

and are just starting their family planning process but they have actually never been

tested for PKD and sometimes that's because the parents themselves have very mild

disease and they haven't told their family. So how does that conversation kind of

play out? So at what point should an adult with PKD tell their adult children so

that they can start this process and how does that conversation look in your

practice? because I find that it's one that we have a lot

>> Yeah, so I see adults for lots of different genetic conditions PKD I would say fits

also into kind of the same category as like cancer I see a lot of patients for

personal or family histories of cancer and there is obviously because people love

their children and love their family members this desire to not worry them and not

make them anxious and just let them live their lives without any of these concerns.

But besides even the fertility side of things, we know that it's important for

people who are at risk of PKD to protect their kidneys as much as possible, right?

And so that doesn't start at the time of a diagnosis, that really should start

beforehand. And so Even if their adult child doesn't want to know if they have PKD, they should be made aware that there's a possibility of 50 % chance, and they should be taking

actions to protect their kidneys, whether that's staying, you do this counseling all

the time, way more than I do, staying hydrated, avoiding nephrotoxic medications, are

sort of the basics, diet, those types of things. But what I also tell people who

have adult children who might have PKD is that I think a lot of them don't know

that there are things like IVF available and they just don't they think it's

inevitable like inevitably this will be passed on and it'll just keep going on and

on and on and there's nothing they my adult child can do about it Anyway, so why

even bring it up, but that's not correct. You there are options available and we've

already talked about them a little bit here. And so in genetics and I think in

medicine in general, we are in the space of giving people information and allowing

them to have the autonomy to do with that information what they please. And so

that's kind of the conversation I would have with that type of a person to say,

you know, listen, one, we're missing an opportunity to protect the kidneys of your

adult child. Two when they find out because they will. They will eventually find out

that may hurt your relationship with that person that person may feel like listen

You knew this the whole time. I could have been getting medical care I could have

been talking to my partner about what this means for us and our childbearing Do we

want to have children? Do we want to do IVF? Do we want to do a donor gametes?

Do we want to adopt? Do we not want to have kids at all? If you give that

information too late, they've already had kids, you know, that can really lead to a

lot of resentment. And so I really encourage those people to treat their adult

children like adults and let them have information that allows them to make the

decision that's best for them because not telling them doesn't necessarily lead to a

better outcome or less anxiety than letting them know and giving them some agency to

do something about it.

>> Yes, absolutely. I think it's important to let people feel empowered in their own healthcare, especially around a time of family planning.

So is there anything following pregnancy that is specific to the care of an

individual with ADPKD? Is there anything special that they need to do postpartum or

any risks that they need to consider?

>> So in the postpartum period, just like in the pregnancy, there will be close attention paid to blood pressure monitoring and if the pregnant person, again, is the one with PKD and the potential development of preeclampsia after delivery. So we are concerned about that up until about six weeks of pregnancy, so it's not a time to lose touch with your obstetrician team and your renal team. You know, the other consideration is if you are on some of the medications that we know are now, not the blood pressure medications, but other medications that we know are now able to be used in people who have PKD, we know we cannot use those in pregnancy. But if you were someone who was considering those medications, you know, it might be a time to decide am I done with am I done having my

Children? am I not done having my children? you know when when can things like this

be be used in in my case and so again a time to have like close close connections

with your renal team and obstetrics team to decide kind of what what's next for you

>> Is it necessary for the baby once born to follow up with a pediatric nephrologist,

or can that be delayed you know later on in life? At what point do they need to be

screened for PKD themselves if you didn't do IVF with a genetic testing?

>> Yeah, so it does become a little bit complicated from a genetics perspective when we have children whose parents are known to be positive for an adult-onset genetic condition.

We do not typically do genetic testing for those children because again,

we have this idea of Autonomy like they get to make that decision. Obviously if

something was seen on ultrasound prenatally then that needs to be followed up and

that could lead to this idea of you know This postnatal renal follow-up for the

child perhaps genetics appointments as well. But without that, without there being a

concern for the fetal kidneys, there is often not any specific management for the

newborn. And we would suggest that they, you know, be screened for PKD when they're

much older. And that's typically just with ultrasounds and not a genetic test

necessarily unless they're old enough to sort of give consent for that type of

testing.

- Okay, great. So we basically only screen for cause, not just because the parent was affected.

- And that can be a very hard conversation because obviously IVF can be cost prohibitive for a lot of people, very involved, and might not be something they want to pursue, but that doesn't mean that they don't want to know if their child has PKD. And so it is definitely another reason for preconception discussions, right? Because it is likely going to be the case that the team taking care of that new baby will have these discussions and say,

"Well, we don't really want to color their childhood with this information about

what could happen to them." And so we don't typically do extra testing just because.

>> So we've talked a bit about genetic testing. I think for a lot of individuals,

the concept of genetic testing is actually a little bit confusing. So could you talk

to us a little bit about what the process of genetic testing actually looks like

and what genetic counseling is available and how an individual with ADPKD could get

the most out of this information?

>> Definitely. So ideally, when you are seeing a genetics professional, there's sort of two

groups of people-- genetic counselors who are masters-trained individuals who learn

about genetics, but also learn about sort of the ideas of helping people through decision-making processes and being sort of culturally competent, as well as sensitive to people's

values and and you know feelings about some of these complicated issues.

And then there's geneticists like me who are physicians who go to medical school and

train to be not only there to help counsel patients about what genetic testing is

available and what it can tell us and not tell us but also do sort of full

evaluations of those individuals to do physical exams and you know know if a

particular group of symptoms fits with the genetic condition or not. So if a person

comes to see a genetic geneticist or genetic counselor there's ideally kind of three

phases to the process one is a pre-test counseling phase in which the genetics team

will ask a full history Get Information very detailed history about the family.

They actually draw out something called a pedigree which is like a family tree so

we can understand relationships within the family and how genetic conditions or

features of genetic conditions may be passed on. We also talk in that pre-test

counseling session about risks and benefits of genetic testing. So coming to genetics

does not automatically mean you have to get a genetic test. We talk about What type

of testing we want to do how that testing works what it looks for what it doesn't

look for and then you know Sort of what types of results we can get back because

it's not always positive or negative and Then lastly in that discussion we talk

about insurance coverage. You know what are the laws around insurance and what you

know What are the expected costs going to be for you for that genetic And then if

a person or a couple wants to go forward with genetic testing, we are able to

order the testing for them. Those results come back to us within a few weeks. And

then we have a post-test counseling session where we share those results. We help

to make a plan for that individual, which specialists do they need to see or give

them a list of things to share with their primary care doctor. And then we also

can offer what we call cascade testing, which is testing other family members. And

so all of those things are meant to help the person walk out of that visit with a

plan. We also of course try to connect individuals with patient organizations like

the PKD Foundation so that they can reach out to people who have the same condition

that they have or have family members with the same condition because often those

people are going to be much more helpful than we are answering their questions about

just how to live their life day-to-day with that particular condition.

>> And so this whole process is still possible even if somebody doesn't necessarily know

their family's medical history such as the cases where somebody may have been adopted

or if they have they're the first in the family that has this mutation. So this

process would still be the same for the same for those?

>> Yes, we would recommend anyone who's considering genetic testing try to be hooked up with a genetics professional to have that thorough evaluation. And families are complicated, and so oftentimes there isn't a lot gleaned from the family history, but it is

still a very important part of our process. And you're right, it doesn't eliminate

the possibility of that person getting genetic testing, particularly if they have

symptoms or a clinical diagnosis you know then the family history is is less

important but it does tell us about prospective people right like just because we

don't know about the people right before it does tell us about the children in the

family or the younger people in the family or the siblings and so that can be

still informational and helpful for that post-test counseling session.

>> And in this case the family that is yet to be when we're talking about the family process, the family planning process. Excellent. So very helpful information. I think definitely

worth getting hooked up with a genetics counselor. And for those who live in more

remote areas, or may not be near a center of excellence, or an academic center that

has a genetic counselor available, are there services that have genetic counselors

that can do like remote telehealth services, or do they all have to be in person?

>> Yes, genetics often can be done via telehealth, especially for indications like PKD.

A lot of genetic counseling was done via telehealth even before the pandemic. And

so, you know, if you're sort of wondering, where can I go to get this type of

appointment? There's a couple of things I would recommend. One is talking to your

nephrologists or PCP. They should be knowledgeable about a genetic counselor or

geneticist in their area or that they reach they can reach out to if not Especially

for the person who plans on becoming pregnant their OBGYN often can have Connections

to at least a prenatal genetic counselor who can perhaps point them in the right

direction and then there is a national organization of genetic counselors called the

National Society of Genetic counselors. And if you go to their website, it's nsgc

.org, they have a spot on their website called Find a Genetic Counselor.

And you could plug in your zip code or your area, and you could find genetic

counselors that might be able to to see you or help you out.

>> Excellent. So it's definitely very helpful for those who need to be engaged or want to be to be engaged in their care and their management, especially around this family planning

process. So for individuals with ADPKD, some are more prone than others to get

complications like urinary tract infections, kidney stones, pain from their cysts.

Is there a more frequent occurrence of any of these things in pregnancy for patients

with ADPKD? And if so, how do they get managed during that process?

>> Yeah, so those are definitely things we need to keep in mind if we have a patient

we're taking care of with PKD in pregnancy. One important thing to know is that

renal disease that doesn't typically worsen during pregnancy it typically remains

stable unless there's pretty significant renal disease before pregnancy so that's why

it's important to you to get those things monitored and under control before

pregnancy happens. And we know that kidney function may also worsen for some reason

in people who have been pregnant at least four times. And so that is something to

also have an extra discussion about before pregnancy. In regards to urinary tract

issues like UTIs, we know in general in pregnancy asymptomatic urinary tract infections are

more common. We do typically screen for UTIs in pregnancy all along the way. We

also know that kidney infections can be common in pregnancy and UTIs can progress to

kidney infections if the UTI is not treated. And we treat those with antibiotics

that are safe in pregnancy, so it's a very similar treatment, but it is important

to get those treated early before they progress to kidney infections 'cause that can

cause more issues. Kidney stones and cyst pain are also possible.

They're not necessarily more common, but they are possible. And treatment for that is

very similar to what it would be outside of pregnancy, including the use of narcotic

pain medication if that's what's necessary to sort of get through that acute period

of pain. And so we are, we are comfortable using those medications in pregnancy and what to be able to treat your pain and not worsen things. And then as far as things like

liver cysts go, people who have like multiples, twins, triplets can have maybe an

increased incidence of liver cysts, but those obviously should be monitored by the

multidisciplinary team to make sure that they're not worsening and causing more pain

or difficulty.

>> And so if you just had to recap really quickly quick and dirty

summary of what is needed for those with ADPKD for routine standards of care for

testing during pregnancy outside of a routine pregnancy for someone without ADPKD. what

would you say the most important factors for or talking points for your patient to

have with their provider during that time? Like if they had to go in with a list

to ask their provider what should they make sure they include first and foremost?

>> Yeah, so hopefully their provider knows this already but it's always good to come in

with a list and make sure that they're checking off these items but at an

initial prenatal visit in a pregnancy for someone with PKD we need to make sure

that we get what's called baseline preeclampsia labs. So this includes a complete

blood count, looking at your hemoglobin and platelet counts, liver function tests,

looking at the liver enzymes, a uric acid, renal function tests,

which most people with PKD are very familiar with so that we know what your

creatinine level is. And then we do an evaluation for proteinuria with a 24-hour

urine collection to count up how much protein is present in the urine. Those labs

may be repeated later in pregnancy if high blood pressure or higher blood pressure

starts to develop. We also would recommend treating the blood pressure if there are

blood pressure issues with medications that are safe in pregnancy. Ideally, those were

started prior to pregnancy, and we will continue to titrate those medications and

increase if necessary as the pregnancy goes on. We also recommend a prenatal aspirin

or what's an 81-milligram aspirin that's taken at the beginning of, or towards the

end of the first trimester. So at about 12 weeks of pregnancy, an 81 milligram

aspirin once a day to prevent preeclampsia. And then finally, to monitor the fetus,

what's recommended is to do ultrasounds assessing the growth of the baby so after

the usual ultrasounds at the beginning of the pregnancy those growth ultrasounds

happen about every four weeks in the second and third trimester looking at the size

of the baby and then also assessments of the fluid levels around the baby.

>> Excellent. That is a nice, summarized description of what is needed and I like that.

Is there Anything else that you would like to share with our listeners today, Dr.

Reed, any final words that you'd like to share?

>> I would just say that people who have these medical conditions,

genetic conditions, there can be a lot of normal feelings around pregnancy that get

sort of heightened because of pregnancy and so it's important to recognize that each

person's care should be individualized. You should make sure that you have a team of

doctors that you feel like you can talk to and that you trust and that the

decision that one person makes with PKD is not necessarily the decision that you

would make and you need to feel free to be able to have those conversations with

your care team and with your family to make sure that you are making the best

choices for you and feel the most supported.

- I think it's really reassuring that there are providers out there like you who are leading the efforts to making sure that this population is well cared for. So thank you for all that you do for the PKD population. I think it just about wraps it up for me. It's been a pleasure having you here today. Thank you for spending this time with us and sharing your insights on family

planning and prenatal and Conception and pregnancy care for the population with ADPKD. I'm sure they find this very, very helpful.

>> Thank you

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The Foundation funds research, education, advocacy, support, and awareness on a

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