

## Communicating with Your Health Care Team

Elise Hoover: All right. Looks like it's time to get started. While Dr. Lakhia is putting up her slides, I'll go ahead and do a little intro. So, I'm Elise Hoover, I am your hospitality host for this session. Welcome, everyone. We are here to hear Dr. Lakhia. Talk about communicating with your healthcare team. If you have any questions, we'll do our best to have a Q&A at the end.

So, please type them into the chat box. You can type them in and send them to everyone or just to me if you feel more comfortable doing that. And looking forward to the presentation, I'll turn it over to you, Dr. Lakhia.

Dr. Lakhia: Thank you so much for this opportunity. I'm really excited to be here today and talk to you a little bit about how to communicate with the health care team. So, let's see here. I have no disclosures. I am an assistant professor at the UT Southwestern Medical Center here in Dallas, Texas, and I lead the PKD clinic for the last several years.

And then in addition, I run a research laboratory as well to study Polycystic Kidney Disease. And I'm fortunate enough to have the PKD foundation as part of my funding support. So, let's get those things out of the way. So, how do we communicate with our healthcare team? I think this, this leads to a lot of questions. And you know, even from my own personal experiences, I find that there are things that we can do better from both ends of our spectrum. And so just kind of the objectives of this discussion is really to understand which health care professionals really need to be part of your team when you've been diagnosed with Polycystic Kidney Disease, and then how to assess specific healthcare needs and determine which healthcare team members should be consulted.

So, who do I talk to for what and when do I do that, and what's the best way to communicate such that, you know, I feel that I'm being taken care of the way that I need to be taken care of. So, there are many complications of Polycystic Kidney Disease. And that often leads to an individual needing multiple different, doctors. So, for example, the kidney and when he applies

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this to kidney disease, we talk about you having to assist in your kidney. So, this is an MRI image and where you can see that these are all the cysts that are in the two kidneys. But what you can also see is that the same structures are in this area over here, that's actually the liver. So many individuals have liver cysts.

So, they need a liver doctor or even a transplant surgeon sometimes for this particular purpose. Another type of doctor for individuals with Polycystic Kidney Disease is a pain management doctor. And this is simply because as you can see, this is a normal kidney here, but this is the cystic kidney. And you can see how big that kidney can sometimes become not for everybody, but for some people. And that can lead to a lot of strain on your back and your muscles and things like that. And so specific pain management therapies and approaches really are indicated for individuals with Polycystic Kidney Disease, because there are medicines that we really don't want you to take, you know, that are available over the counter, they can actually damage your kidneys and we don't want that to happen.

And then another complication that often happens is that you develop a kidney stone. So, you know, individuals without Polycystic Kidney Disease, develop kidney stones, but those that do have Polycystic Kidney Disease also can develop kidney stones. And then, you know, you oftentimes are referred to a urologist which is a surgeon that takes care of kidney stones, or an all and or, and – or a kidney stone expert that can actually help look at your urine and decide, are there certain risk factors that you're that you know, you're eating certain foods and things like that, you know, that may be predispose you to kidney stone. And then are there ways for us to get around that and to modify your diet to reduce your risk.

Some other special sub specialists that oftentimes individuals may need are a cardiologist. Just because with Polycystic Kidney Disease, you often wind up with high blood pressure. And then in addition, you can have manifestations that happen within your heart such as Valve issues and things like that. Most common one that people know about or think about is the complication of having an aneurysm in your brain. So, this is the MRI of an

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individual and this is the brain vessels and then this little balloon right there that's the aneurysm because the individual has Polycystic Kidney Disease. So, they need a neurosurgeon, you know, and then some others that you know, are not so often talked about, but do exist and are actually quite common are cysts in your pancreas, or even having just a hernia in itself.

So, you can see there's so many different doctors, so who should really be on your team? Do you need all of them? So, in my opinion, you know, I think if you have been diagnosed with this disease, you need a PKD specialist, you know, an PKD specific nephrologist, you need a local kidney doctor or nephrologist so as you know, many individuals live really far away from an PKD center or from a PKD specialist.

And so, you need it's really in your best interest to have also a local kidney doctor that can help you with some of the things that are very common to all individuals with kidney disease, and then they can communicate with your PKD specialists too, as well. You need a good primary care doctor that you trust, and that you can go to. And then you need your family and your friends. Because if you can't do this by yourself, I mean you can, along with your team, but I think that the experience is much better if you can develop if you have that relationship with your family and friends to also be on your health care team.

Who else do you need? Well, it really just depends. So, here are a few examples of individuals who need different have different needs. So, Sally is 32 years old, she was diagnosed with Polycystic Kidney Disease when she developed lower back pain. And she found out she had a kidney stone, actually, kidney stone did not pass on its own. So, unfortunately, she required surgery to take out the stone. And she doesn't really have any other complications of Polycystic Kidney Disease.

So, who else does she need, in addition to those four individuals that I just stated, are urologist and a kidney stone expert to reduce her risk of stone, but she doesn't at this point, need a cardiologist or a neurosurgeon or anything like that. Let's look at our next case. So, Ben is 42. And he has known he has

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ADPKD. Since he was 20 years old. He recently developed some headaches that were new. And so, an MRI was done. And it showed that he had a small brain aneurysm.

So, he needs a neurosurgeon in his team of doctors to help him deal with aneurysm and decide what the next steps are. So those are two simpler cases. What about this, this is a little more nuanced. So, case number three, Elizabeth she's 60 years old, and she noticed that her abdomen was increasing in size. But she was losing weight because every time she tried to eat, she felt like she was just full right away, she could never eat a full meal. So, she saw her primary care doctor and he had a CT scan, and he noted that she has Polycystic Kidney Disease and polycystic liver disease as well.

And it really seemed that most of the bulk of her abdomen was really due to her liver. So, at that point, because she was losing so much weight because she couldn't eat properly, even though her liver was functioning properly. Based on her lab work, you know, we really needed to refer her to that hepatologist and the transplant surgeon because there's a special scenario that exists for individuals with polycystic liver disease whether it's due to mutations that cause Polycystic Kidney Disease or polycystic liver disease mutations themselves, that if your liver is so big, that you're actually losing weight, and you have sort of what we call failure to thrive, you may be a candidate for a liver transplant at that point, even though your liver is technically still working.

And it's a PKD specialist that really can kind of remember to keep that part in mind because this is not something that routinely that we think about all the time. And then this is this is sort of a last case of a very complicated situation. So, Amelia is 42 years old. She has unfortunately very aggressive Polycystic Kidney Disease or kidney function is already at about 18% of what it should be. She has high blood pressure, and she underwent an EKG and that was abnormal when her primary care doctor recently did a routine exam. She's overweight and asking if there is a body mass index cut off or a weight cut off before she can get a kidney transplant. And finally, she reports that she took her dialysis education classes and she wants to do peritoneal dialysis

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if she does not get a kidney transplant before her kidneys completely fail. So, who else does she need so she needs a cardiologist because her EKG was abnormal, she needs to be part of the kidney transplant program.

So, when your kidney function is less than 20%, we routinely refer you for evaluation for a kidney transplant as a way to start making sure that it's safe to give you a new kidney, or are there other things that we need to do to prepare you for a potential kidney transplant, she needs to speak with a weight management group or a weight loss specialist to talk about her weight loss because we know that being overweight, maybe something that's detrimental for Polycystic Kidney Disease, but also it may preclude her from being able to get a kidney transplant and she's being very active and wanting to know the answers to those questions and prepare herself.

And then finally, you know, she is very aware of the concept that she may have to start dialysis before she gets a kidney transplant and she's chosen to do peritoneal dialysis. So, she needs to be in touch with a good surgeon who understands that peritoneal dialysis is definitely an option for individuals with Polycystic Kidney Disease and can be able to place that PD catheter or peritoneal dialysis catheter when it's time to be placed.

So, as you can see from these four cases, your extended team really is determined on based on what you need, and these needs may change over time. You know, as you get older, your needs may change some of the needs that you had, you may not need any more. And so, this is sort of a list of some of the most common referrals that I place in my clinic and groups that I work with on a routine basis, closely to manage individuals with Polycystic Kidney Disease.

So how do you prepare for your appointment with your PKD doctor? So, before your appointment, I would really advise you to write down, you know, kind of all of your questions or things that you need to be addressed at your visit, especially when it's your first visit, you know, you want to make sure that you can kind of feel that you all of your concerns were addressed. And if it's possible, try to send these questions or concerns to your doctor

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beforehand, you know, now with the electronic medical record system, it's really easy to shoot your doctor a message, and you know, oftentimes the nurse gets up first, but you didn't say, "Hey, I am scheduled to see you in two weeks. But you know, these are the questions that I definitely am going to have.", especially if you have quite a few, you know, and then that really helps, at least me prepare for my visit with my patients, because then I can, you know, I have an agenda of things that I want to address and take care of for each of my patients.

But you know, if there are additional things that I can plan our visits, such that we make sure that everything is addressed, and answered, you know, in a fashion that, you know, our my patient is well taken care of, you know, and so it's one of those things that write them all down. And you know, as more common than that, what you also don't forget, one of the most important things to do is to always keep a list of all of the medicines and supplements that you take, you know, you can even just take pictures of your pill bottles, bring them with you, you know, and especially if you're taking some supplements that are over the counter and bought at specialty stores, bring them with you, or bring the ingredient list because we're not familiar with all of them, new ones come out all the time, they change their names, things like that. And, you know, we just want to make sure that what you're taking is safe for you to take.

And then, especially when you're a new patient, bring your records from your other doctors with you, you know, oftentimes you move from one portion of the country to another portion of the country. And we are always more than happy. And we asked for these records to be sent to us. But as you know, and we know, it sometimes takes a little bit of time. So, if you have CDs, if you have records, bring them with you. Especially one of the things that not everyone may be aware of is because of this federal law called the Cares Act that was passed in the last two years or so, our patients should be able to see in many scenarios, not all the time, what are what we have, as doctors have written about a particular visit. And that should be accessible to you in some,

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you know, one-to-two-week timeframe after your visit or even the same day as your visit.

And these are records that you can keep, and you can bring them with you, you know, and that will be a quick way for you to kind of be able to tell your new doctor or your other doctors what has been going on. I know that onus should not be completely on the patient and their families. But I think that when we work as a team, where we make our effort to get all of the records that we can, but if you can bring what you have as well, sometimes it speeds up how we can take care of you.

So, what do you do during your appointment? Make sure you ask all of your questions. Repeat the answers out loud, you know, and if you can't repeat the answers, if you don't understand, just ask again, we all come from different backgrounds, different doctors use different terminologies, you know, and so just because you went to a particular physician, and they, they told you something, and your nurse took that a completely and then you went to see someone new because you moved or something like that.

And they say something, and it sounds completely different. And maybe that we just use different words for it. And, and so just ask, you know, and we're always learning how to become better communicators to make sure that we are, we understand each other. And so, make that clear, because it's very, I will say it's very disappointing and frustrating to me, because when my patients are too scared to tell me that they just didn't understand, because I'm always more than happy to carve out extra time to make sure that we do understand.

And I think all of your PKD doctors are like that. And we want to make sure that you understand because that's that knowledge is the power that that you'll be able to understand why we're suggesting certain things or telling you not to do certain things and, and things like that. And if you don't understand that it makes it really difficult to follow what, what someone else is telling you to do.

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So, that being said, again, don't be shy, you know, we use a lot of medical words. And you know, and there are no real silly or unnecessary questions, everyone is at a different stage in their knowledge about their disease. You know, some individuals are brand new, it's a brand-new diagnosis that you know, and better you're here today at this conference.

And for others, you've known that you've had it or your family members had it for many, many years and you're very well versed, and so everyone comes with a different level of understanding and so it's important that ask the questions you know, and ask the questions that you know, you may even think are silly like is it supposed to really hurt hear you know, or, or someone said this, Do I qualify for this? Or sometimes just say you know, this medicine you know, if you just doesn't make me feel good because if you don't tell me I don't know. And I really - I want to know that and because that's the only way we can, you know, come up with a plan that works for you.

So, on that note, you know, be honest, there really is no, no judgement, we want to have a relationship where we trust each other, you know, and so it we all, everyone is human, we all understand things, things happen, especially in the last several years with COVID. And us having to do so many visits that are virtual, or individuals having hardships in their lifespan, they aren't able to always take care of their health. But just to say that, you know, I didn't take my medicine today, or I haven't taken it in three months, because I can't afford it. Because that will help us come up with solutions to finding ways that you, you can afford it, can we change it to something cheaper, as did your insurance change, and we need to change something, you know, because our goal is really for you to have the best outcome. And there really is no judgment, but we don't, we can't just, it doesn't work well, when you just say that "Hey, I am doing everything." If you're not, we'll just keep adding medicines.

And then one day, if someone - I've seen this happen, where an individual one winds up in the emergency room, and they have a list of medicines that they are taking all of them. And so, then the doctor in the emergency room



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says yeah, if they're taking all of them, I'll just start them all, and then their blood pressure becomes really, really low, and they get really dizzy and lightheaded. And unfortunately, they, were not taking all of them, you know, and so we want to have an area safe space where you can just be honest with each other, there really is no judgement, we understand we want to get you to a place that everything works for you.

So, then, from an exciting standpoint, ask what's new, you know, Polycystic Kidney Disease. You know, I feel like we're in a time where there are so many exciting things going on. And I think you've had this opportunity to see some of this at the Connect Conference this weekend.

In the last decade, we have a drug that's FDA approved to slow down the disease. And so, ask, do you qualify? Why do I not qualify that will provide you some, you know, additional understanding of the disease? Are there clinical trials that I can sign up for? If you if you as the center are not offering them? Is there another center? And is that something that I should look into?

I read on my Facebook group this or the Twitter feed that or actual research journalists, what do you think of that, I think that it is very great good to be empowered about what your disease is, if you're at that stage to learn more about it and want to participate, because I think that will really drive you to want to, you know, embrace what different interventions come out and things like that. And as a physician, I always find it very satisfactory, trying to know that, you know, my patients are really quite on top of what's going on. And, and sometimes, you know, if I didn't read the newspaper this morning, or if I didn't, you know, check my journal article at seven or eight o'clock in the morning, and I go to clinic at noon, and they bring it to me visit this came out today. It's quite, it's from a very biased perspective, it's very quite satisfying to me, as well to see that the community is so involved in wants to know.

So don't hesitate to ask what is new ask every single time. So, some other things to do during your appointment is, you know, take notes, and listen, you know, to what the discussion is about, it's there. So sometimes, especially when it's your first visit, or as your disease and if your disease, unfortunately,

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progress and things become a little bit more complex, there's so many different moving pieces, that it's really easy to forget. And we all do this. So, try to try to bring something to take some notes, you know, we always try to provide you with a piece of paper at the end of kind of an action plan. But write your own notes as well, you know, and then and then listen, and if you know, if you can consider bringing a family member with you, especially if you're nervous, you know, it doesn't hurt, to have another pair of ears, to listen, and to help understand what is said, you know, we all understand things differently as well.

And sometimes they think of questions that that you or I didn't think of either, you know, or some logistical things that you know, may make the interventions that we're considering as a team, not feasible or ways to make them more feasible if we think that they are not feasible.

And so, it's always helpful to do that. So what do we do after or when you know, kind of are walking out from that clinic, make sure you have kind of that action plan from your doctor, you know, whether they say we didn't change anything, everything looks great, or we ordered these tests, or we're changing these medicines, make your next appointment, even if it's, you know, a year out so that way at least it's in the books, you know, if you need to change the date, no big deal, but at least you haven't been lost in the system, you know, and mark on your calendar or on your phone, you know, if you're supposed to communicate back with your doctor, you know, oftentimes we say, okay, let's change this medicine, check your blood pressure for a week, come back and let me know what it is.

Or we say, okay, we ordered that MRI for you. Let me you know, let me know when it's done and that way, we can make sure we have a follow up appointment for you.

Ask how each doctor communicates with the rest of the team. So, it's really important when you have Polycystic Kidney Disease that your primary care doctor and your PKD specialist community Get with each other, and we routinely send our notes to each other. So, we know how things are going to

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ask that each doctor sends, you know, all of these other sub specialists that you, you may or may not see, send that communication to both your primary care doctor and your PKD. Specialist, I think you can see that, you know, oftentimes, you know, the PKD nephrologist, winds up doing some portion of that primary care, just because there are some complexities and, you know, unique needs of individuals with Polycystic Kidney Disease that we really can help the primary care doctor out with making sure that you get the right referrals, but it's important that all of that information is sent to both the both sets of doctors, so they know exactly and can keep tabs of, you know, kind of coordinating all of your care and seeing what order things are done in.

How do you reach your doctors? We live in a world where, you know, back in the day, you had to call on the phone and leave message and they said, okay, well, you know, the doctor will call you back or something like that. And that that actually still exists, you can still call the doctor and you know, but there's also this electronic medical record system.

So, it's important that you ask, you know, each member of your team, how do they prefer to be reached? Do they prefer to get a phone call? Or do they prefer to just kind of use the electronic system? If they use that electronic system? How do they how often, you know, should? How quickly should we expect a response? And who is checking it? You know, because in every scenario is a little bit different, you know, some systems are set up such that, you know, you may receive a response the same day, you know, and depending on the scenario, other times, it may be several days.

And so just knowing how to where to set your expectations of which method to use? And then what if you have a hard time reaching them, you know, and then you eventually do just let them know that, you know, I tried this, but I didn't hear back, you know, for this long. And sometimes, you know, we are all human things fall through the cracks, or was trying to make our system better. And so let us know and see if there's a simple solution, you know, that perhaps there was something on our end that we could have done a little bit differently. So that way we can, you know, make sure that you were able to reach us or, you know, there was a break in the system. And then we can tell

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you that, you know, we apologize, this is exactly kind of what happened. And so, you know, we were working on that not happening again.

So, who do you call for what? So the way that I think about it, and I think that will work best is if you think it's related to your kidneys, you know, call your PKD specialists, you know, oftentimes it's like blood in your urine, really bad back pain, you know, your blood pressure is not controlled, you're having some swelling in your legs, trouble breathing, things like that, then they can guide you as to what are the next step to do? Okay. If the question is regarding specific complication of Polycystic Kidney Disease, call that sub specialist so if you know you are having a unfortunately need a pain management doctor and you're on pain medicines, and the pain medicine isn't working, go ahead and call them they can help troubleshoot that. Or if you think it's a side effect due to a medicine that they prescribed because they warned you about it, you'd say so or in similarly to your liver doctor, to your neurosurgeon or your cardiologist.

What about some general things, I have a cough cold, what medicines to take, you know, something that I don't really think is, you know, you don't really think is related to PKT start with your primary care doctor, it's really important that you have a good primary care doctor, someone that you can reach, because they have the bus system set up for off hours answering questions and, you know, directing you to the right place to go and things like that.

And then anything that's related to particularly prescribed medicines, speak to the provider or the clinic that prescribe the medicine, you know, and the refills really should only come from the doctor that prescribe that medication only and this is in your best interest, because then it keeps everything very straight, and so that way, you know, the doctor that's prescribing, it knows that they're the ones that are refilling it and that nobody else hopefully is doing that. And so, they know that you've been on it for this long, and that you continue to be on it. And then they're the ones that are changing the dose if you need to and things like that.

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And that will just keep all of your, you know all of everything in in a particular order and would lead to less confusion. And then finally, if it seems serious, you know, everyone has a great sense of you know, when they know themselves best, and if they really think something is wrong, don't hesitate, just go to the nearest urgent care emergency room for evaluation.

So, what are some of the action steps after you know, this presentation here today, I would suggest the most important things that we do is start keeping a list of you know, questions, concerns for your upcoming appointment, you know, just keep a keep a little book and then you know as things come up, if they're not urgent, you can just kind of keep them together and say, oh, yeah, I heard this. Let me just write this down. organize all of your medications and supplements and then keep a record of all your physicians their contact information, who you see, and things like that. And just that way it, I think it will be best served to keep it all organized. And then finally, I will take any questions, I really appreciate your time today. And I listed my contact information here in case anyone wants to reach out.

Elise Hoover: Excellent, thank you so much for that presentation, we have a lot of really interesting questions. So, the first was about getting all the different specialists to communicate. And you talked about making sure everyone has all the same information. One example we had was maybe two doctors just disagree on the kind of medication you should be taking; how do you advise someone handle that?

Dr. Lakhia: So, you know, we should talk to - the doctor should talk to each other? You know, you should definitely ask why they disagree. So that way you understand me, we're all very smart individuals. And so, you know, that way, you kind of get a sense of why. But you know, this, this does happen. And I this happened to me this this week, as well. And, you know, I always say that, you know, just let me know who it is. And then I'll ask my nurse, you know, reach out to them. And, you know, we will be happy to discuss, you know, what is the best course of action? And then we should both be getting back to you with the exact same resolution, you know, would be the most ideal scenario. I know that that doesn't always happen. But that should be the goal.

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Elise Hoover: And do you have any guidance on someone who has heard that perhaps you should get a nephrectomy or have a polycystic liver removed and getting differ differing recommendations from different doctors? Do you have any advice for us on that?

Dr. Lakhia: You know, I think it's always good to ask for another opinion, and do what's right by you, if you if you're getting conflicting opinions, asked for a third one, you know, and see if it makes sense to understand you know, and sometimes I will be honest, there's not always a clear cut answer, you know, and so, you know, both answers may be correct. And then then we have to, you know, decide, what's the best for you as an individual, you know, and, yeah, it's a difficult situation, I completely understand.

Elise Hoover: What about any tips for when you first get a referral to a new specialist? How best can you set up that relationship? And, and get the care you need?

Dr. Lakhia: Good question. So, you know, I think it's great when you have, so say, for instance, you have a new referral, you call and you make that appointment, just go ahead and ask them, you know, can I send you some records of what I do have, what do you need, can I go ahead and sign the paperwork, so you can request my records, because I will say, in my personal experience, it works out. So, I think that the patients also enjoy it much more when everything that can be sent has already been sent to me.

And I've been given the opportunity to review it. And so, then the first visit is extremely productive. I think oftentimes, you know, given our system, we don't always get all of that information. And oftentimes, the first visit with a specialist, especially if it's, you know, we'll say, oh, you've already had this study, but I haven't seen it yet, rather than making you do it again, let's get those records. And then we'll decide what to do next. And then you leave thinking, well, what was what was the point of this visit, if you didn't have the information that I needed anyway, so if you can help us get the information, I would really appreciate it, I know, the onus should not be completely on you. But being I think it's very important to be an advocate for

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your own healthcare. And so, if you can, you know, facilitate that, that would be really helpful.

Elise Hoover: And what about a clinical trial doctor or study team and your regular doctor, what kind of interaction should they be having?

Dr. Lakhia: So, usually, there's almost, you know, very little interaction, you know, in the sense that, if you are, for instance, let's say, you're in a clinical trial that's at a different center, you know, they don't are under no obligation to let me know that they're in the trial, you know, it's usually you as a patient that tells me that I am in this clinical trial, where they are under obligation to make sure that you're taken care of as part of a clinical trial as if something comes up during the trial, you know, that needs to be addressed, then either they themselves or they can send the patient back to, you know, a different doctor and let them know that hey, this came up during the trial. But, you know, because of specific privacy rules and trial rules, you know, we don't specifically communicate with each other and it's not something that's routine. Yeah.

Elise Hoover: Here's a question. Should someone ask their nephrologist how many PA patients, do you see? Is that an important thing to ask?

Dr. Lakhia: I think that I mean, I don't think any nephrologist would be offended by that. If you asked me five years ago, I would say, well, you're my, you're my first, two or three, and now that answer changes over time. And so yes, you can ask them. And I think that so many of our great nephrologist in the community, say, you know, I see so many, but I really prefer that you also see a PKD specialist who and then we can work together, you know, because they, they have the most recent tools, and we can help you.

Elise Hoover: And there's a question here about PKD specialists say, in a certain area, so you Texas, are you all talking to each other? What are those relationships look like between different PKD specialists?

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Dr. Lakhia: So that's a great question. So I have, you know, as a young or PKD, specialist, compared to many in the rest of the country, you know, and growing our clinic here at UT Southwestern, I have no hesitation asking for help, or answering questions and things like that, if I've entered, you know, something that's not routine, perfect PKD, and looks a little odd to me, I have no hesitation reaching out to you know, mentors, or leaders in the field, asking them, "hey, I have this case, I'm not quite sure. What do you think, how do you do this?"

And so, we do have a relationship where we communicate with each other, we also, when patients move, you know, we, they need to find a new PKD specialist, we have no hesitation sending them on to the next specialists, you know, and so we do all talk to each other. And then also because of the foundation, you guys, the Foundation does a great job of trying to integrate us and knowing that we all do exist. And so sometimes we just don't know, you know, who is where it especially newer and younger places. And so, we do all talk to each other.

Elise Hoover: And you mentioned, you know, being honest with your clinician, and, and, you know, helping facilitate the conversations between maybe differing opinions. But there is, of course, a fear of maybe angering your clinician or your care team and that being held against you as a difficult patient or, you know, how do you advise someone to think about that about, you know, advocating for themselves, even if it does bother someone on the care team.

Dr. Lakhia: Yeah, I think, you know, we all have our own opinions, and we all want to do what's best in class by us. And sometimes, you know, it's not, there's a conflict, I understand, you know, between the physician or the team and, and the patient, they do or don't want to do something, right, like the patient themselves do or don't want to do what the team wants, or the team do, - does or doesn't want the patient to do particular thing. And so, in my experience, I find that it's best to be cordial, kind and respectful. You know, and if you are cordial, kind and respectful, and can communicate that I do, or don't want to do what you're asking me to do for these reasons, and I'm not going to do it, you know, but if you can say it, and then in this way, as opposed to in an



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angry way, I personally would not be upset as it okay, I understand our goal, at the end of the day, you know, you are your you know, your own person, and you have to do what's best by you, I can only advise do what I know, based on my knowledge.

And if that means that we you know, are completely different, and you want to see someone else I would be more than happy to send you to someone else, because I want what's best for you, you know, and not, everybody get along, gets along with everybody. And that's okay. You know, and so but I think approaching it, trying to approach it without confrontation is probably the way to achieve the best outcome, because then we can both respectfully understand that we have differences and then try to find a move away to move on.

Elise Hoover: And how would you advise someone who, you know, we know that there are people who are diagnosed with PKD in childhood, so maybe they'll see a pediatric nephrologist? What should it look like once that child ages into adulthood needs an adult nephrologist? Should that be a seamless transition? How should that look like what kind of questions should you be asking?

Dr. Lakhia: Yeah, exactly. So, I think it's good to start preparing, you know, when your child or is around 16, start talking to their nephrologist, say, hey, in two years, you know, who am I going to see next, you know, and then that way you have some idea of what your nephrologist plan is.

And if you do or don't want that plan, you have time to change, you know who that is moving forward and then you have sort of a seamless transition to move on to the next nephrologist. And so that way that your pediatric nephrologist can send your records to your adult nephrologists, you know, and often centers have kind of a collaborative relationship with the, you know, pediatric nephrologist and the adult nephrologist are good friends, and they say, hey, I'm sending you one of my patients next week, you know, and we do talk like this. And this, that happens very often. But we want that seamless transition that is very critical and important, because that age of 18, you're about to go to college or start a job and things like that.

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And you have to learn to kind of take some responsibility of your own health problems. But you still definitely need some support from your family who has been taking care of you with this disease for this long. And so, it's really important to have a good transition at that time. And hopefully, you don't need to see the doctor more than once a year. And you know, when you come home for summer break, or whatever it is, but I think it's really critical, because that will give your child that opportunity to grasp and have developed develop a quick, happy relationship with their nephrologist that they will be able to sustain on their own and know what that expectation is before they're kind of led off to do it on their own.

Elise Hoover: And what would you say to someone who has an adult child who is not yet diagnosed? You know, there are concerns around accessing life insurance, for example, you know, how would you advise someone, if they're thinking about assessing a family member for the disease?

Dr. Lakhia: So, it's a really personal decision, and there's not a right or wrong answer. And the reason for this is because there is not a cure for polycystic kidney disease. Yet, if there was a cure, we would say, well, let's find out so we can give you the treatment for it. But because there is not, there's a lot of fear around being diagnosed, because of things like life insurance, you know, whether you will still be covered under your medical insurance plan. I mean, we have that protection right now.

But we may not forever, and things like that. And so, what I generally advise, you know, parents is, you know, you have to decide with your child, you know, what is best for you. And so, if you choose to find out, we can go and find out with the expectation that if you go and try and find out that answer that they don't have, it may not be definitive, because sometimes if you have very mild disease, we may not know for sure that you don't have it.

So, that's one thing to keep in mind that you may not be just kind of given a clear frame of answer right away. And the second thing is that if you choose not to find out, you know, your child should continue regular health care, which means once you're well child checkups with their pediatrician, and if

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something comes up to suggest that they're having a complication such as a kidney stone, or if they find out they have high blood pressure, at that point, it may be reasonable to start looking into whether they have this disease because we want to slow down the progression of it. And if you're starting to have complications, then it is important to find out so we can start treating it to get the best outcome possible.

Elise Hoover: And with that in mind, say you are someone who is your kidney function starting to decline, you're just seeing your usual nephrologist. At what point or should you ask to see a PKD specialist?

Dr. Lakhia: So, I think now, everyone with PKD should see a PKD specialist at least once, you know, just to know if they will, it's personal preference. But if they want to know how aggressive their disease is, since only half of the individuals that develop ADPKD, develop kidney failure and the other don't, many individuals want to know which half they fall in. And if they do fall in that aggressive half. How, when is this going to happen? And we have the tools to do that. And so, I think that, you know, at least once you should see a PKD specialist and then decide how frequently you really need to be seen by PKD specialist and maybe once a year, maybe once every two years, hopefully, you know, or maybe more frequently, depending on what your specific needs are.

Elise Hoover: Could you also clarify for us how you diagnose someone with ADPKD?

Sure, so the diagnosis officially is based on knowing what your family history is and what your imaging findings are. If you have a family history of polycystic kidney disease, we look at what your ultrasound or MRI shows, and we have a criteria based on how many cysts that we see whether or not you have the disease and we can rule it in or rule it out. If there's really no family history, the diagnosis becomes a little bit tricky, because if you know and to officially call it the disease, we often have to do genetic testing to find the mutation that's causing it.

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Elise Hoover: And let's see, there is a lot of research coming out right now about the benefits of certain diets, in slowing disease progression. If you're interested and what that would look like for you. Maybe it can be challenging to find a dietitian, you know, what do you advise for starting that conversation with your doctors?

Dr. Lakhia: So I would advise go ahead and say hey, how do I you have a dietitian that you have access to me you know, most places will have access to one or they can refer you to a dietitian, you know you should also take that extra step and maybe see what kind of coverage your insurance provides for a dietitian as well, because there may be a set number of visits that your diet that you're that your insurance will cover. And that will help frame what your discussion is going to be about with that dietitian as well, to determine what, what the cost will be, you know, many insurance companies do pay for dietitian counseling, and some unfortunately, don't or you may have to pay out of pocket. But just, you know, don't hesitate to say, hey, I need a dietitian to help me out.

Elise Hoover: Are there any other specialists that you think are key to an average patient aside from nephrologist?

Dr. Lakhia: you know, I think if you have a nephrologist, and a primary care doctor, you know, those are those are the those are the keys because then the both of them will know who else to send you to. And we you know, our goal is not for you to have 15 Doctors if you don't need them, you know, we just want you to have the doctors that you really need.

Elise Hoover: Excellent. I think we've addressed all of the questions. Is there anything else that we would like to ask Dr. Lakhia before we sign off? Right, you're also welcome to message me on the platform Elise Hoover, or email [research@PKDQ.org](mailto:research@PKDQ.org). And we can make sure to get any other answers for you as well.

And then we have a 20-minute break. And then we have our final session of the conference, the plenary it's an update about what the foundation's been

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up to my boss, (Chris Rusconi) will be presenting on a new program we're launching this fall. So, I hope you will join us. And thank you again so much for joining us for this session. Thank you, Dr. Lakhia. Yeah.

Michelle Tarczy: I had another question.

Elise Hoover: Oh, sorry, Michelle, of course.

Michelle Tarczy: Yeah, sorry. I was asking when I was diagnosed with PKD. It was done via ultrasound. Is there a genetic test now or bloodwork that can be done to diagnose it? Or is it still an ultrasound?

Dr. Lakhia: So, it depends on the situation, we do quite a bit more genetic testing for the diagnosis, but we need to see what your kidneys look like as well. The testing for ADPKD is little bit complex, because the genes that cause polycystic kidney disease, the one that caused most of it PKD one gene is one of the biggest genes in all of our DNA.

And on top of that, it has a few extra copies that look like that, but aren't actually the PKD gene. So, the testing that we do is not 100% Perfect. And so, it's possible if we do a genetic test on you, it can come back either it can come back negative. But when we look at the pictures of your kidneys, we see that you have many sets. And so, it's really a combination of family history, what your kidneys look like, and then potentially looking for a mutation by doing genetic testing as well.

Michelle Tarczy: Okay. All right, question. So, after all that's done. Is that, does that give you a more definitive answer? Or still not completely so?

Dr. Lakhia: Good question. So, if you say for instance, you said, oh, my mom or my dad had PKD. And then you come in to see me and we do an ultrasound for you. And you have cysts on your kidneys, you know, that meet a particular criteria based on your age, that is sufficient for me to diagnose you with the disease, I don't have to do the genetic testing, you know, but if you come in and you say, no one in my family has ever had this disease, you know, nothing like anywhere close to it.

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And then your ultrasound shows that you have cysts in both of your kidneys, I would say Okay, it looks like you have Polycystic Kidney Disease, we can do genetic testing, to look and see if you know what mutation we find. But there are some limits of the tests that we may not get a definitive answer. And so, if we do the test, and then we find a mutation that has been specifically, I would say you know, kind of certified as a mutation that causes the disease, then we can be sort of 100% confident that this is exactly what you have.

The reason this is becoming a little bit more important now is because there is JYNARQUE as a one drug on the market to slow down the disease. And in order to qualify for it, you have to have officially have polycystic kidney disease as a diagnosis, in the past, you know, we didn't have a specific therapy. And so, at the end of the day, I could say you have polycystic kidney disease, but you have ADPKD specifically, you know, or something a little more nuanced. It didn't change what I did for you, you know, and now because that there is a drug on the market, more coming more clinical trials, things like that, moving forward, it's we're becoming a little bit more picky of saying that you have that definitive diagnosis. And by me, I mean, insurance companies are becoming much more picky about knowing that you have a family history, you have a mutation testing, confirmation.

Michelle Tarczy: Interesting. And lastly, is there a certain age that you would start to test again, as an example my kids are 15 and 12.

Dr. Lakhia: So, it's a personal decision. And, you know, some families want to know right away or as early as possible, and others don't want to know, you know, out of just, you know, fear and or fear of, you know, life insurance and other astigmatism and things like that, or just even mental health purposes. And so, I advise all of my patients that makes sure that their kids get routine health care checkups. And if something goes up, then maybe consider, you know, pursuing to find out, you know, whether or not they have the disease or not, and then otherwise, you know, it's a really, it's a personal decision that I would not kind of step in the middle of.

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Michelle Tarczy: That makes sense. I just didn't know if the tests were geared towards a specific age or starting at a certain age, or if it can be done at any age, basically.

Dr. Lakhia: Yeah. So, if you want to know that you don't have the disease, you know, if you, if you have, say, for instance, you have a sister or something like that, and she wants to give you a kidney, you know, and she says, I don't I've never been checked, I don't know. And she's only 35 years old, you know, if we do an ultrasound on her, and she doesn't have any kidney cysts, I cannot at that point be 100% sure that she doesn't have the disease, because we really want you to wait till, you're about 40. We can be 100% Sure, if we try to do genetic testing to see if she has the same mutation you have, you know, and so there are kind of layers to this to see.

Michelle Tarczy: When I first was diagnosed, they said, up that everything can show up until age 30, that if you didn't have by 30, you were in the clear, basically. So, now you're saying it's 40?

Dr. Lakhia: Yeah, we really like to wait until you're, you know, 40. I mean, if you were 30, and you had nothing, and it was really completely clear, I'd be pretty confident. But I would be still a little hesitant to let you know someone give that kidney away just without understanding that there are risks that they may still have some mild disease or something like that.

Michelle Tarczy: Sure. Makes sense.

Elise Hoover: Well, we are at a time everyone, Michelle great questions. There is though a link in the chat of a survey, if you would mind giving us some feedback. This is the second time you've asked Dr. Lakhia yet after this presentation. So, we want to make sure we give her good feedback so we can improve next year. And we'll see you the next session in 14 minutes.

Michelle Tarczy: Awesome. Thank you so much

Elise Hoover: Bye everyone. Thank you.

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*[Audio Ends] [ 1:17:15]*