So before we get started, if you have any questions, go ahead and type them in the chat box and we'll get through as many as we can during the Q&A session after the talk.

And then we also ask that you please keep your microphone muted so that we can make sure we have good audio quality.

So I'm very pleased to introduce our speaker for this session, Dr. Ronak Lakhia is an assistant professor of medicine, in the division of Neurology, at the University of Texas, Southwestern Medical Center in Dallas, where she also received her medical degree.

Dr. Lakhia leads the PKDF clinic at UT Southwestern where individuals with PKDF, other genetic disease, kidney disorders, receive comprehensive individualized care. Her research, laboratory focuses on understanding the metabolic and epigenetic factors, underlying adpkd’s severity.

Dr. Lakhia, it’s my pleasure to turn the presentation to you.

Thank you so much, at least for the kind introduction. Well, thank you everyone for joining us today, and thank you to the PKD Foundation for this opportunity to all of you about a very important aspect of PKD care which was communicating with your with your health care team.

You know, I've had the privilege of training here at UT Southwestern and studying polycystic kidney disease and as part of my training, when I joined the faculty, I actually open the clinic here and it is what I've learned from my patients over the last several years.

Through this clinic that I'm going with you today. You know, it is you that has influenced what has kind of molded in my mind what is the best way to communicate and assemble your healthcare team. And so, I look forward to the questions that you have and hope kind of build on that as well moving forward let's get started. So this is a disclaimer, and I have no disclosures.

And so what are the two main things that we want to talk about today?

The two main things that were really are on the agenda for us to discuss is what are the healthcare professionals that need to be included as part of your healthcare team?

You know, I'm sure that this is a very broad audience of those that are, you know, extremely educated and know everything about polycystic kidney disease. And then there are those that have just recently been diagnosed and are learning about this, and so it can be overwhelming. And that's one of the things that we're going to address today.

And then the second topic is how do we communicate with our Healthcare professionals? And how do we, who do we call for one and so I hope that you know through the next you know, 25 to 30 minutes we could go over that and then I want to take your questions and really see your viewpoint and what is it that we can do to do better.

Now, as we got started as a reminder for and maybe a little bit of a refresher, there are many complications of places you need to that all of you deal with and everyone knows with different complication. Here are a few examples.

One of the most common places that we see these this outside of the kidney is in the liver. So, on the left here, you see that this individual has many liver cysts, and sometimes those liver cysts are so bad that they cause pain and complicated.

And then you need to go see a liver doctor. So that's called a happy collagen, you know, that is one extra doctor.

In addition, your kidneys develop these cysts and they can grow quite large. And this is a very burdensome disease, often times. And pain is a very concrete problem that many individuals with PKD have.

So you may need to see a pain specialist or even a pain specialist specializes. Another example are kidney stones, Kidney stones are more common in individuals with polycystic kidney disease compared to other disorders and you may need a kidney stone expert or a urologist if your stone gets stuck.

How about a few more? And you can see how this be can become overwhelming in complex. One of the most feared complications that we think about is the concept of an aneurysm in her brain and do you to see the neurosurgeon.

What about the heart? The heart also has this mutation is in your whole body and so you may need to see a cardiologist for several different types of effects that your heart may have. Sometimes you may have cysts in your pancreas. Some individuals have a hernia as you can see over these two slides, there is a slew of doctors that you may potentially need to see. But do you really need to see all of them just because you have PKD? The answer to that is probably not.

How do you decide and who should really be on your team? So as part of developing, this cclinic here at UT Southwestern, you know, I realized and I understand the importance and I want to emphasize the most important thing, I think you really need is the four doctors. And four groups of individuals I’m going to list her.

number one is your PKD specialist and this is someone who really is that person in your corner who knows all of these complications that can happen. Who knows who to reach the, right people who have an expertise pkd, and the liver pkd and the heart and who can get you to that right place.

Now, I understand not everyone lives by a pkd center. We don't have one on every corner and we don't have one in every city. So many individuals do travel, far, and wide. Do you have to have one? I think it would be great, have one that you'd see hopefully once a year or, you know, if your disease is milder or you don't need too many things, maybe once every couple of years. But then you do need a local nephrologist. And often times, even when you have a pkd specialist in your area, you may work with your local nephrologist as well.

And so it's important to have a kidney doctor near you. But you do need someone who really understands this disease especially. Now I would say if you asked me 20 years would that be the case, maybe not really given how little we knew about the disease we know so much. And yet, we knew so little and how little we could do about it.

But now so many things, as you've seen in the conference, are changing our knowledge has gained so much. And there's so many exciting options that may potentially become therapeutic out there or different interventions that you can do with diet and lifestyle and things like that.

So, I think that benefit of having that pkdf specialist in your corner,

At some point in your, you know, in your lifetime with polycystic kidney disease is really important.

I think it will give you a valuable tool in your box of understanding a little bit better and helping coordinate.

But in addition to that, you need a primary care doctor as much as the pkdf doctor and the kidney doctor want to be your primary care doctor.

Unfortunately, they don't always have the resources to help take care of those things that not necessarily have to deal with the kidney or something else. If you want a good primary doctor.

Especially if you don't live very close to and kidney doctor or a pkd doctor, having a good primary care, doctor that communicates with the kidney doctor can be would be in your best interest.

And then finally, your family and your friends, I think this is a very, very important component you need support to deal with and whether it's friends or family, it's very important that you keep that time too.

Will you have that support or develop it through conferences, such as this. Developing friends like that help you through and understand because it's a very helpful to have an extra year, I personally have learned over the last several years of taking care of loved ones’ medical illnesses.

Our healthcare system is extremely complex, especially when you see multiple doctors in different places, because here, I am telling you to go see the pkd specialist and then, you know, but that system is different than the primary care who hasn't had this practice for 30 years in is a fantastic function but their charts are on paper and having all of that together and coordinating that. But have a group of family or friends that helps you, listens to you, knows what's going on, and helps you navigate that can really be a tremendous asset to you.

So how do we decide who needs to be on your team?

You know, and we've been over this a little bit, but let me give you a few examples of something because it really just depends.

So, here's our first case, Holly is 32 years old.

She was diagnosed with polycystic and she develop some lower back pain. And she found to have a kidney stone. She went to the emergency room, and she didn't passed a kidney stone, and she needs surgery to take the stone out.

She didn't have any other complications of pkd because the pkd specialists that she saw once a year went over and asked the questions. So who does she need to see in addition to the primary care doctor and the kidney doctors? She needs to see the urologist to make sure that her kidney stone was removed and also a kidney stone expert.

There is such thing as a kidney stone expert who is not a surgeon that had can help reduce your risk of developing future kidney stones.

And so that is someone that we referred her to understand what is causing her stones. Is there a way to change her diet? Does she need to drink even more water than she's already drinking? Is there any medicine that will help prevent her from getting more kidney stones?

Let's go to the next case. Case #2. Ben is 42. He has known he has ADPKD since he was 20. He hasn't had any problems, but he recently developed some headaches and he told his primary care doctor who knew that he had ADPKD and she reached out to the pkd specialist and said let's get another MRI and it showed that he's developing small brain aneurysm. We saw that and we sent him straight to the neurosurgeon to take a look at. It was monitoring and evaluating. He didn't have any other complications so he didn't need to see any other doctors at that particular time.

We go to the third case. So, Elizabeth 60 years old, and she noticed that her belly was getting bigger, but overall she was losing weight. Why would she losing weight? She was losing weight because when she tried to eat even though she was hungry, she couldn’t get any more food down.

She saw her primary care doctor, you know, did CT scan and he saw the polycystic kidneys but he also saw the polycystic liver. And when they sent that over to the pkd specialist and we started asking more questions.

We realize that her liver was taking up so much space and that can happen sometimes in individuals with polycystic. If it's their liver then that is the bigger problem. You can potentially get a liver transplant because you're losing weight and that is a quality of life issue.

And in that particular scenario, we sent her to the liver doctor, the hepatology and the transplant surgeon.

And they said, yeah, she meets this very special criteria because of the bulk of the liver and she received a liver transplant, and is doing much better.

And then finally your needs and change over time. So for example, Amelia is 42 years old and she has pretty aggressive polycystic.

Her kidneys are only working at 18th kind of what they should be. She has high blood pressure.

Her EKG, to look at her heart, was a little bit abnormal when she saw her primary care doctor. She's overweight, and she's very educated about polycystic kidney disease and she knows she's going to need a transplant so she’s asking is there a limit? How much I can weigh to get a kidney transplant? Is that going to keep me from getting a kidney transplant?

And then finally she wants to learn about dialysis and she wants to do cardinal dialysis when her kidney fails, if she hasn't responded. So who does she need to see? She needs to see the cardiologist about her abnormally EKG. She needs to be referred to the kidney transplant program because her kidney function is less than 20. She needs to see a weight management group because she’s very active and she wants to get a transplant and she planning for this ahead of time.

And then she needs to see the surgeon so that way when she needs that dialysis catheter placed she knows who he is and they know that it’s safe to put the dialysis catheter when it's time.

So essentially, you know, her kidney doctor, no pkd doctor are working with this team here at everything. Ready to go, such that he can have a kidney transplant. He can be placed on a kidney transplant list and if she needs a transplant. That everything is planned and there are no emergencies.

And she doesn't need to start dialysis or become very ill.

So as you can see that extended need really be determined on what you need. And this can change over time.

This is a lifelong disease.

And so this coordination of care by your pkd doctor and and your primary care doctor is impenetrable in deciding who you really need on your team over the course of your lifetime.

And this only lists only really includes their physicians and health care team members that you may need from a pkd genetic disorder perspective.

You may have other conditions, other medical problems, and those members may need to be on that team as well and all talk to each other.

So how do you prepare for your appointment with your people? You doctor. I just told you there's a list of many doctors that you've made potentially has found out that you have places bikini or maybe you've had it for some time.

But no, we really haven't had any problems.

Did you think that you need these?

Someone said you had liver cysts. Do I need a liver doctor? How do I do all of these?

If you can try to send them to the doctor beforehand in an electronic records system where you can send a message them. Say Dr. So-and-so. I'm going to see you.

I just want to send you my list of questions ahead of time that we can discuss when I come.

You know, this is extremely helpful because really even if they only had ten seconds to look at it before, then it gives them an idea of where you're coming from, and if there's a difficult questions, you know, then they can have some time to find the answers and your visit can be more productive, although we're more than happy to answer, you know, they will come back and talk to you.

Sometimes that's a little filling for the patient.

They will my questions asked did not get answered, but if you have the questions before, then it gives your doctor a little bit more time to put everything together and see where you're coming from.

Make a list of all of your medicine supplements you take and take pictures of bring them.

So this is extremely important when you see multiple doctors and different healthcare facility, we don't know exactly what you're taking because the electronic system’s communication with the pharmacy is not a hundred percent perfect. And so,

someone I always go over that list with that us with them just to make sure that we clean it up and it looks proper because it can change and we know that it will change but bring what you're taking so that way you know what it is and even every single supplement that you bring as well,

Common things I'm asked about is, is okay to take a particular supplement and there are so many out there right now.

It is difficult for me to keep up with your things and think and I'm very worried that what you're taking actually may not be safe. And inevitably we say, please send me the label, you just bring it with you or send a picture with it.

That is incredibly helpful because we want to make sure that what you want to take or what you heard about is safe for you. And that's why you're showing us as well.

Bring your CDs. I know you've seen many doctors from many places. Bring your records with you from the other doctors.

If they gave you a piece of paper after you saw the heart, doctor is in that zone assume that we got the information as well. Bring it with you. If you have it I'm not telling you to bring the whole portfolio but bring the few things from the last video that you had or writing down.

You got some pictures or if you were in the ER for some reason and they did a CT scan. Bring it and we will upload it into our system and we'll have it on file as well, because every piece of information that you

Give us, you know, is one more information about you that we found though.

What do you do during your appointment?

Now you're here, you made that list of questions, asked all of them, get the answer, repeat the answers out loud. You make sure that you understand them, if you don't understand ask them again, you know

Ask them again, you know, as a population, the individuals ask the best questions. You know so many things and you ask some very tough questions

And sometimes we don't do a great job explaining and so asking again and make sure that you get that answer that you want you know. Then we will simply say we don't know and we will find out and get back to, you know, the community is very cohesive. Both from a patient perspective, community perspective and then from the physician and the scientist perspective and it is very easy for any of us to reach out to someone

Patients, ask them, have you ever seen that? Someone asked me this.

What did you say to that?

No.

And so that's what I always tell my team or my patients with that.

And I don't have the answer.

I have the ability to reach out and when you get me, you don't get me at my institution and then you also get the pkd team. We have no hesitation out to each other for advice or answers.

So, please just ask all of them.

Make sure you understand what the answer is. Ask what the meaning of these medical words are. There are no silly or unnecessary questions. Do I qualify for this medicine? Is it supposed to make me feel bad? You need to say so because until you tell us that some of these are going on, we don't know.

And everyone is different than medicine. That a thousand people take that, they have no problems with you. You may have a problem. Be honest, there is absolutely no judgment whatsoever.

The physician is a human being and they may not know everything and maybe they will say, so, you know, and at the same time, you know, it is much easier to just say, you know, doc something bad happened. We know life happened. I haven't taken my medicine in a week and a half.

That makes complete sense.

No, of course, you know, it's unfortunate that that happened but that at that and makes me understand why your blood pressure was high. When you came to clinic or things like that. We do figure things out. We know sometimes things happen but it's a lot easier when you just tell us what is going on because there is absolutely no judgment. You know, we really understand that everyone's life situation has is different and stressful especially within the last year.

And so you know finding a way to make your health care and make do well with environment that you had is what we have to work with. And it's different for everyone. And the best way to cater to that is for us to have a relationship. When we understand where you are coming from and where things are not working. So we make everything work.

Ask what is new?

I really encourage you to ask your pkd specialist and your kidney doctors what is new.

This is such an exciting time for people and I know many of you read all of the science and the articles and the newsletters from the foundation about what is new. Because maybe it makes it for a very exciting conversation when you can see what’s there and as you develop this relationship with position, you can see how those new things are progressing.

You know, there is research out there, there clinical trials out there.

Do you qualify even if you're not interested, if you don't want to be in it, but this know that, it's, they're coming for you.

How are the drugs approved? Do I qualify for them? You know, one of my favorite things that that happened was a few years ago with a paper came out in a scientific journal. And the next morning I got three messages from patients who have no science backgrounds, who had seen it and they asked my thoughts about it, you know, and I'm not saying you need to find papers, but the fact that these things catch their eye, and you have questions about them to see them, you read it on a blog, ask about it, ask what is.

So you need to find papers, but the fact that these things catch their eye and you have questions about them see them you read it on a blog, ask about it. Ask what is new because it keeps us on our toes and that's good and it actually will make you more involved in the care that you [inaudible].

What else should you do?

You know, and understand the answer to the questions but write it all down, you know, or write as much of it as you can write down, you know, we kind of make a point to write down the most important things for you to take home on a piece of paper.

But listen to what would you know, what health care team is telling you write down the notes to the best of my ability and, you know, one of the things to consider, especially when you have new things going on is to consider bringing a family member.

Especially if you are nervous. You know it's there's something new going on or things are not working and you're frustrated bring a family member with you because sometimes it is a lot of information. Especially if, unfortunately, your kidney function is declining and we're heading towards transplant or dialysis. If your pain is not controllable, things like that can be really, really burdensome.

We know bring someone with you to help you answer or write down things so that way you don't feel like you're taking all upon yourself. Then what do you do after your appointment is make sure that you understand when you walk out that door, what the plan is, you know, it can be overwhelming.

But I understand if you ask the doctor to kind of go over it with you or the nurse that she's checking it out like what are the few things that you need to do.

You have your next appointment, are the medicines that needed to be changed or adjusted for the referrals that. Know you're supposed to go back. Often times, we ask you to reach back out to us. Let us know how you're doing with your new medicine or with your blood pressure

Write it down on your calendar. It is easy to forget. Sometimes, you know, that you think need to be done, but reach back out to us because we are thinking about you. We worried and want to know how you feel. And it’s anxiety - provoking. At least for me when I don't hear back from you and then I go back and start calling you find out what is going on. Often times, most of the time, it's because things are just fine and that's why I haven't heard from you but we want to know about it.

And after that appointment, mark it on your calendar what you're supposed to do and communicate back. That actually builds the relationship to know that we're going to get that information back from you. It gives more leeway about how much we can do from going back and forth through electronic party like that.

At how do all the members of the team communicate with each other?

If you have to see multiple different doctors, you know, if one person's easy, for example and they just wanted your medicine. Then you go see a different doctor and that the adjusted again. How do they know? Ask all of your doctors to send communication to your primary care doctor, you pkdf specialist, and if you also have a kidney doctor, your kidney doctor. So that way they can see all of those things. Even if it's a small, as simple as getting a colonoscopy because it was ridiculous or if you had your mammogram or something like that. But ask them to send all of that to the primary care doctor. And then, to the pkd specialist. If you had hip surgery and knee surgery, let us know that these thinkgs are happening and it all goes in your chart. And we see that it is our job also to communication back to, you know, to your primary care doctor as well about what is going on and what our plan is. Ask them to make sure that they get sent.

And then how do you reach your doctor. So one of the things that I would recommend is that you really ask each member of your team how they prefer to be contacted. Some offices prefer to get a phone call. Others prefer to send a message through the electronic medical record system.

If you have a hard time, seeing a team member, let them know and see if there's a simple solution. If you sent that message to the electronic medical record and you just haven't heard anything back in a full frame, then pick up the phone and give them a call.

Sometimes there's some simple solution. There are glitches in the system or maybe that person was out and he never saw it.

But if your concern is urgent and needs to be addressed, don't hesitate to reach out and tell them, you know, I did do this. What is a better way for me to do it because it didn’t work itself out. And sometimes there, oftentimes, there is a very simple solution of what is what it is that we do. So that way we don't have that glitch in transition of the time span of what is going on and then who do I call for what.

In an ideal world, you have this primary care doctor that takes great care of you, and you have a pkd specialist who wants to do everything for [inaudible]. But they're hard sometimes [inaudible] or you’re not close to then.

So, what do you do? If you think related to your polycystic [inaudible]. Call the pkd specialist. Some examples include if you have blood in your urine, really bad back pain, blood pressure that’s been under control and is no longer under control or if you have swelling in your legs amongst other things. You as a group are very smart and you know when you feel like it's your pkd is that’s the problem. So call them. They’ll tell you what are the next steps to do. Often times it is telling you to go back to your primary care doctor because they can take care of you within 20 minutes.

And then we work with the primary care doctor to see what's best or to send you to the emergency room. But first, call them if you think it is [inaudible].

If it's something that’s related to a complication of your pkd like for instance have already been seeing a pain doctor and your pain medicine is no longer working or if you’ve seen a liver doctor or heart doctor reach back out to them.

Go ahead. You don't have to start with start with the doctor that you think. You are very smart group of individual and, you know, your body best. So go ahead and start and look out for to them.

What about the regular cough cold? I'm tired. Do I need to see a specialist every time I have something [inaudible]?

No, you don't. Start with your primary care doctor. If you have a question, if they start you under medicine you're not sure if it's [inaudible] just ask them. They’re very aware and they will check and if they're not sure they will read that. I commonly receive phone calls, just double-checking, make sure that it's ok to proceed. If you have any other concerns start with that primary care doctor.

And then if you will, if it's something related to medicine, or if you need a refill on a particular medicine, try to get it from the doctor that prescribes, and the reason that's really so important, and I know sometimes it can be a juggle, if you have multiple doctors is because we want to know that I provide this for you and then now you need a refill which means that you're doing well with it or that or things like that or if it's not working or are you even still taking it?

And so, that way, it helps us keep track of you, you know, that we're refilling it, because we're the ones that are helping to manage that particular medication, okay?

And then finally, it seems serious, you know, go to your nearest, emergency room or urgent care center.

You know what it is. You know, your body best and so take that time and go ahead call your primary care doctor on the way and let them know what's going on or afterwards.

Or if you wind up saying it’s related to your kidney. You have concerns, ask the your physician to call your pd doctor. And I commonly received phone calls, letting me know that someone so came this was going on. Or if I have some additional recommendation of what should be done.

But you know your body best and we really do trust you to understand when it is an emergency, especially when it's, you know, after hours. And it's a little bit difficult, get ahold of your primary care, doctor, it can be, it can be a scary situation. Sometimes I can understand that going to the nearest facility is perfect.

But finally, after all of this and before we bring up some time for questions.

So, what are the most important things I want you to take away from this?

I really want you to start keeping a list of your questions and concerns, you know, maybe just keep it driving down to the side, you know, if you see your doctor every six months, or once a year or something, so add it as it comes, you know, organize what you're taking your medicines or supplements and then keep a record of al of your physicians’ contact information for all of them, so that way you have a very good-go [inaudible] and to be comfortable asking questions.

So with that, I would really like to thank you for your time, you know, and it's allowing me to [inaudible] something from and what I have learned over the last five or six years about, ,you know, about community and how to have a successful relationship with our patients and to have them succeed in their healthcare. And then I really like to take any questions that you have

I have a question.

Yes.

Doctor, look here, my name is Karen Solomon, Edwards. And I would, I'm very thankful for this presentation that you presented.

It is very vital information. As you were talking, I was listing the name, I have a total of eight or nine physicians.

They're all at a major complex in the city of Detroit.

The the information that you provided, most of it I know now after eight years. Had I known this at the onset, I think my journey, my kidney journey would have been much easier

I encourage all of my fellow kidney patients that we have to be more active in our care.

Because what I have encountered is that with all of these eight doctors [inaudible] I had to learn all these different names.

The kidney doctor, the transplant doctor, the neurologist endocrinologists, all of those doctors, some of them are not communicating and they're all on the same system and they're asking me these questions and they're especially not communicating [inaudible]. And as a result, I was prescribe a medicine that the other doctor told me a month ago don't take this.

This causes diarrhea. Then I go to this doctor. They prescribe it, they said, just try it for a month. I tried it.

That one day I had diarrhea, so the problem that I see and then there are some caring and concern doctors, but the problem is, they're not communicating.

There's no communication or either they're not looking at the medical records to see what the other doctors are prescribing of what was said because my medical history is like a book long and I think it's all there, but they're not. What do you suggest?

You know, I completely understand where you're coming from.

Like I said to my, even my personal experience through my family, I have first-hand seen in the last two years, how complex and frustrating it can be to navigate the healthcare system as an outsider as a non-physician.

Then that advantage of me being a physician that helped me see some of these ways to kind of make it happen is still incredibly frustrating. I think, I think it starts with the core and that core really needs to be you need to have one doctor

One doctor that really knows everything, you know, and be able to have that kind of center help you that and you be part of that center with your family, you know. But yes, you have to be active in your health care and you need to have that and you need to have that one person that is able to know all of those things, you know. And I will be very honest with you.

I mean, even when it's in one system sometimes, you know, who this, there is some lack of communication, we're still trying to learn to make this work from our end. I'll be very honest with you.

You know and [inaudible] had to despite our best efforts you know that communication doesn't make its way through. We talked about this: how do we make that better? And we are getting better over time.

We're trying our best, but having that one doctor, I would suggest having a really good primary care doctor that has all that information and for you to let that doctor or the either, the PKD doctor and send them a message every time you go see someone else. And that will be that record for you, you know? And so that will be that put together for you right there because sometimes you are the best advocate for yourself and we really need you. Just like the internet and information overload that we get.

Now in the real world, our medical system is sometimes the same way and we need to be able to be able to put together. We need your help with me, on us, know that it's the most successful that way.

Yeah, great question, Karen.

Dr. Lakhia. I think it was a really excellent presentation. I have a few other friends that have come through on the chat and if you wouldn't mind, just go ahead and put those questions there and we do a little bit of a queue of questions and make sure we get to as many as we can.

The first one if I could just feel the first one is, you know, I know with covid, we've had really different concept of using telemedicine for managing disease, and you know how and do you use telemedicine in your practice and appropriate reason to see dr. Of telemedicine is opposed and in clinic visit. Great question.

Yes, we use telemedicine in our clinic, we switch to that. And now we combination of both, you know? I think that you need to see a doctor in person.

You're otherwise, relatively healthy at least once a year, okay, you know, and then when you see your pkd doctor, I actually want to see you in person at least one. Okay.

With covid it has been hard to see new patients in person right away.

We're still transitioning back to everything in person as much as we can.

But I've had many patients that have seen brand-new during the covid time point.

And we said, okay, next time you come I want to see you in person because I really do need to see do you have swelling in your legs? You can show it to me.

We've gotten very good at some of those things, but I need to see once and then we need to make a decision together.

How often do we need to this is person and what can we do with telemedicine through that?

Can be very productive actually. Can let you stay at your job. My patients are on time for their appointments and I'm not late for being any patients either. And it's so in that way, it works very well. You know, it also allows me to show you what your scans look like which we can do in person but I can still do that over television. So now I think we should continue doing some of that especially when you live far away like that but no I really do think that we do need to see you.

I mean, I would like to see you at least once a week, and if you have more complex things [inaudible] more frequently. Whatever's best for you. We have to tailor it to the person sure yeah it's always a conversation

We've had a lot of questions to in the chat about how to know if your nephrologist is familiar enough with pkd to really manage it appropriately.

Do you have any warning signs that someone could tell their nephrologist might not know what they should know for that kind of care?

So, I think the biggest takeaway is that what has changed the moment, and what I tell my patients, that, and 12 years ago, even when I opened my clinic, it was not a whole lot I could say about how aggressive is your disease going to be, when are your kidneys going to fail. All I could really say, is if your parents had an aggressive, then you probably will, or if they [inaudible] things like that. But now we have established rules of how big are your kidneys, will tell you how aggressive disease. We can give you a good estimate of what is going on. You know, and what are some nonpharmacologic interventions that everyone could incorporate into their lives.

Those sorts of ask them about those things and ask if they can get, you know, I really biased because I'm part of the community. And this is what I do is take care of individual may be, but I think everyone should have a kidney volume done to see how their aggressive their disease are. Give them more information. A lot of nephrologist don't have the capability to do that. Not because they can't do it but they don't have a facility. Here at UT Southwestern we can do that but a lot of little places can't. I will tell you that more

Places can't I will tell you that more and more nephrologist are starting to refer to us for those specifically.

No, those are being sort of in some of the questions asked about trials. Ask about the drugs.

Yeah, absolutely.

And you know, and you give some really great tips for ensuring your entire team is aware of your pkd and making sure they're talking to each other. What advice do you have for someone who goes to the ER for perhaps a pain event or something? Where it's harder to find a doctor that you're already familiar with.

oh, go to the, ER, call them that you have places to can meet with you up front and then you know, go ahead and ask them reach out to your kidney doctor while you're still in the ER, if possible, you know, if you're concerned about what is going on.

I understand that if you go in the evening, you may not necessarily get a hold of me right away and bigger institutions. There, is someone on call at night, if you call our institution it will not be me. But someone some other kidney doctor will be able to pick up the phone and get that message, you know?

And sometimes when it's very important and they're going to help you out what it is and if it's something that really needs me, go find me know and things like that.

So you know I would urge you either you directly send a message and go to the emergency room or any tell them that you have.

Yeah. And you know, you've talked about this but it can be really overwhelming and challenging to go through the pkd experience. Getting diagnosed, heading to kidney failure. What kind of advice do you have for your patients regarding mental health or getting support for dealing with just the emotional and social challenges of having a disease like pkd.

First i would say that you are right it is a real problem and no one should miss the mental health component of policies. It is a burden both physically and mental. I acknowledge that it is really good to develop a support system If it is a burden. Talk to a pkd doctor about it.

That is one of the more common things that we do. Discuss if it affects you wanted and it will affect you differently over time, you know. And something that was not such a big deal will become a bigger deal and things that were overwhelming may slowly become less overwhelming. This community provides a lot of support.

But in addition, you know, [inaudible] antidepressant to help you deal with this or any anxiety medicine is not because you're not tough enough to brave it out because that is part of the medical care that you need for your polycystic kidneys. Do not be ashamed of that.

And I think acknowledging it, talking about it and appreciating that it is, okay and will make you have better outcomes for healthcare.

Fantastic. Well, thank you. This has been really a great talk and I appreciate answering your questions.

Do you have any final comments before I end with some announcements?

So I saw one question that popped up and I know there are a lot. Well the one of the ones that caught my eye was and I didn't read the whole thing, but it was about getting insurance approval for tests. For tests that pkd specialist try to order and how difficult that.

So that is changing a little bit because of the availability of [inaudible] and the requirement [inaudible] to have an aggressive disease before you add it. The approval for an MRI for your polycystic kidneys to determine the size that is becoming easier.

If you go to a pkd center, they should have a way to help you get around that.

I tell my patients that you not go pay anywhere else to get that MRI done.

If I tell you I want you to have it done for proper sizes. If they tell you it's cheaper to get done somewhere else, please don't do that.

I won't get the information you need and it will cost you unnecessary money. Call me and I will work together to try to get it approved to the best of my ability.

Now, I understand the cost, you know, even with medicines. But you have to tell me and work with me and then asked, what was I don't do this what will I lose or gain?

And we have to work with that plan that works for you.

Great, thank you for catching that really good question.

Yeah, thank you, everyone else for joining us.