Kidney Failure - What to Expect

Welcome everyone. I'm thank you for joining us.

My name is Meg Munits, and I am your Hospitality Host for this session and this session is Kidney Failure - What to expect. I know this is a really tough one to attend, but I really applaud everyone for coming. It could be really valuable information that we're learning.

It is my pleasure to introduce our speaker for this session, Dr. Fred Rahbari, he is a professor and director of the cystic and inherited kidney diseases clinic at Emory University, School of Medicine. Dr. Rahbari’s research expertise is in the fields of renal cystic diseases, and particularly PKD.

He has been an investigator in several landmark trials in ADPKD, including Halt PKD, Tempo, Represe and the Crisp observational cohort. He firmly supports the PKD Foundation and has been a regular participant in the Walk for PKD, fundraising and patient education sessions in three states.

Doctor Rahbari, it's my pleasure to turn the presentation over to you.

Thank you very much for the kind introduction.

I'm going to try to share my slides with you now. We can see them. Very well.

So as we mentioned, you know, the topic is kidney failure and what to expect that the late stages of renal disease basically. And these are my, the disclaimers.

The objectives are really to go over what are the main signs and symptoms of kidney failure, and some of them you actually don't realize, we picked them up on labs and some of them, you actually feel them and attending this session, hopefully, with the help you to recognize those symptoms and signs and also use some strategies to get some relief for those symptoms.

As a general reminder, the kidneys do a lot of different functions in the body and I'm trying to simplify those in five categories, the first one that everybody understands, you know, you're making urine.

The fluid that comes out of your urine is basically the, what we call volume regulation, function of the kidney that way. You know, you don't get swelling. And you've basically, if you reached the kidney failure stage your urine output will go down and the fluid can build up.

And that's typically a matter of salt and water retention.

Not just water or salt either, or so it's both of them at the same time.

Also, you know, that kidneys are filters, and they regulate many electrolytes, the most important ones are sodium, potassium, calcium, phosphorus, and magnesium, but it's not just those.

And if you do have kidney failure, you wouldn't make.

You may have an electrolyte imbalances particularly on the potassium and phosphorus. But also sometimes a magnesium, calcium, and sodium. The kidneys have a very important role to keep your acid bases at check and in balance.

So, the pH of the blood typically, is regulated by through two organs, they lungs and the kidneys and the kidneys are major part of it.

So, when the kidney function, pretty much goes below 30%, you know, you start having issues with building up acidity, we call it acidosis.

Also kidneys dump toxins out of your body in the urine. And some of these are just the things that you are eating or the metabolites of food, but some are also actually the medications that you're taking and the medications have metabolites and when you cannot get rid of those, you know, because of kidney failure, the toxins build up and could cause several problems.

And last, but not least, kidneys also are an organ that produces hormones, or at least contribute to activation of hormones. And the two major ones are Erythropoietin and vitamin D.

Erythropoietin is the hormone that boosts the bone marrow to make red cells and avoid anemia and vitamin D is basically, what keeps primarily your bones healthy, but it has many other functions as we've learned over the last decade or so. And the reduced production of these hormones can cause problems with anemia and vitamin D deficiency. And also what we call renal or kidney, osteodystrophy.

So those are the main functions of the kidney. This is just a schematic representation of what kidneys are. This is called a nephron which is one single unit filtering unit of the kidney.

You do have a about one to two million of these single units in your body.

So this is extremely small but just to tell you that the arteries are bringing the blood in and out of the filter unit which is called glomerulus. Then you do have the pipelines, which are called tubules, and then, at the end, the urine is produced, and it goes basically out of the kidney.

Again, imagine you have a million of these and then the kidneys are basically getting all of these toxins and water and salt and all those things, filtered and then urine is produced at the other end.

What we call glomerular filtration rate, or GFR, which everybody should be familiar with, is a commonly used term. GFR basically estimates how much blood passes through glomeruli, at the filter level. So at really here, the filter. We're not counting, interestingly, you know, PKD is actually a disease that the cysts start from the tubules, not from the filters, typically, but everybody goes with that GFR to say, you know what your kidney function is.

So GFR represents a kidney function. It's very expensive to actually measure GFR. So what we've done instead is to go to routine lab tests and serum creatinine and serum urea, BUN, what we call the BUN, are the typical ones, GFR typically for a normal person would be between

100-120.

When you're very young, at the age of eighteen, seventeen, eighteen, it could be actually higher than that.

But most people we consider that between hundred and twenty milliliters per minute is the reference range.

So, again, as I mentioned, creatinine and BUN are the two markers, and creatinine is a waste product of muscle metabolism, so you basically is made by the muscles and it's cleared by the kidneys because the muscle mass typically doesn't change that much, we basically take creatinine as a reflection of kidney function, but you have to know that if you suddenly do build up a lot of muscle the creatinine can go up, or if you lose a lot of muscle, creatinine can go down with the same kidney function.

The normal value of zero plan is typically 0.6 – 1.2 point to we usually use that to make it simple one milligram per deciliter, the general rule is that whatever youre creatinine was if you're doubling that your creatinine, your GFR is half of what it used to be.

So if you're going from, let's say, take 1 and from 1 to 2. If you had a hundred percent at one, you're going to 50% at two, if you're going from 2 to 4, then you're down to half of the 50 percent. And then if you're at ten times of and then if you add 10 times of that somewhere between six and ten or twelve, your you've lost more than 90% of your kidney function and you're basically at the point that we need to really talk about dialysis, or kidney transplantation.

Urea is a little bit different in the sense that urea comes from actually degradation of proteins, either the proteins that you are eating or the proteins that you have in your body and you are destroying every day.

The normal value is here is between 8 and 20.

It goes up if the kidney function is worse. But it also, if you start eating a lot of protein, if you have a GI bleed and you have a lot of cells in your intestines that are getting destroyed, or when you're on steroids, or also just simple the dehydration can cause the BUN or urea to go up.

So those are the two common blood tests that we measure for kidney failure. Again for most people kidney failure, has been when the creatinine is around 6 or 7 or above, and the urea of any gets to 100, we usually really start talking the necessity of dialysis.

Now, to make it simple, about 15, 18 years ago, we came up with actually a staging classification of chronic kidney disease because CKD stage

1, 2, 3, 4, 5, it's purely based on your estimated GFR. So if your is estimated GFR is about more than 90 basically your stage one, if it goes between 90 all the way down to 60 is stage 2, to 30 stage 3, and then between 30 and 15 is the stage four.

I mean, when you go below 15 is called a stage five or an end stage kidney disease. Most people here don't have any symptoms of kidney failure, stage 1, 2, & 3. When you get to stage 4 and 5, then the symptoms of kidney failure kick in.

Now in PKD, because PKD comes with a huge package of abnormalities and issues with different organs. You could have symptoms of PKD before this stage but not symptoms of kidney failure. So it's symptoms of kidney failure.

Come here, the symptoms of kidney of PKD itself or here and we'll go over those.

So the loss of function gradually leads to blood tests abnormalities and then you have signs and symptoms.

What you have to understand, and it’s very important, is that the drop in Kidney function is not linear is actually what we call pervy linear.

You have a long face for most people, 20 30 sometimes, 40 years. That you don't really realize that the kidney function is going down.

The reason for that is that again, PKD starts in the tubules, not in the glomeruli, the cysts are tubular and as long as the consequences of those cysts growth is not on the glomerular the kidney function seems to be normal. But when you start going down, then, it's very very palpable to see that, oh, I'm getting worse.

People really start getting anxious, patients, when they see this phase. And then at the end is really almost a nosedive that we're realizing. The relationship between urea, creatinine, and GFR is basically, again, GFR is a linear function, but creatinine and BUN are not. They’re exponential.

So just to show you that if you're, here is your creatinine, so you have 0- 1, which is kind of normal and then, four, eight, ten, twelve, you know, and then your GFR just realize that if you going from 1 to a 2, you've lost almost half of your kidney function here.

So the increments matter much more, when your kidney function is actually good, when you're going from a creating a 4 to 8, you're barely losing twenty percent, or 15 percent kidney function. You've lost most of your kidney function, when you’ve gone up from 1 to 4.

So, from 1 to 4, you've lost more than 70, 75 percent of kidney function. From here to here is another 15%.

So that's what you should not, and that's why we emphasize on using GFR for patients. So they can actually track what's going on.

Now, what do we call kidney failure? Where basically we start talking about dialysis and kidney transplant. When your GFR is basically less than 10 in non-diabetics and PKD non-diabetics fall into that category or if you're diabetic, is less than 15. That's where we really start saying you need dialysis. Obviously, if you wanted to do transplantation, we need to get started way before this stage, usually around 20. And put you on the list.

However, these are the guidelines, but there was a very nice nicely done study from Australia that was actually published about 11 years ago and they basically randomize people in two groups and they said instead of just going by 10 and 15, we're going to actually look at the patient and look at all the other numbers. Potassium, fluid situation, shortness of breath. How they feel? Are they tired? Are they eating?

And if they don't have the major reasons to come to go on dialysis immediately, we're going to wait. We're going to wait until we have a very clear reason. And in that study, basically, instead of between 10 and 15, those patients that were doing relatively okay, they ended up on dialysis between five and seven of GFR and that basically after 18 months of follow-up, there was no difference between them.

So, the take-home message, since then, for me, is that don't just look at the numbers. Look at the patient and hear the patient. See how they're doing, and you may be able to, in many cases to actually wait longer before, dialysis is absolutely needed.

Now, as far as the projection of when PKD, patients are going to end up on dialysis. We have a very nice tool that was developed from the CRISP study and this is the longest longitudinal cohort of PKD Patients was created in 2000. We are on year 21 now and we're going for a couple more years.

So from that study, we basically developed a model that when you take the kidney volume, the total kidney volume, you add the right kidney and left kidney volume. That becomes your total kidney volume, adjust to the height because the kidney size is different based on how tall you are, and that height-adjusted kidney volume, if you project it against your age you basically find a spot on this plot so each of these are basically one single patient.

And we realize that people have smaller kidneys and particularly small kidneys at more advanced age, they do very well. They actually really low slope regressors. Most of these people actually in the class 1A, don't end up on dialysis, they can live 80 years, 85 years, not be on dialysis. So that's kind of, and now we have statement, the class B. 1B, 1C, 1D, 1E.

So you go from the best to a little bit worse. Average, worse than average, and really worst case scenario. And basically, the draw panel drop in kidney function. For each of these categories, is very different. Here you’re talking about half a percent per year, roughly or maybe 1% at the very most. Here you’re talking about 6 to 8 percent per year drop.

So if I see you today in your this category 100% kidney function in 10 years, you could be or 15 years you could be on dialysis. So these are really people that we need to be very aggressive about treating them.

Now we talked about the PKD specific early symptoms, not related to kidney failure, just PKD.

We know that hypertension is probably the most common associated features and usually it's mild, it's not very high.

Some people do have very high blood pressure, but most PKD patients would have relatively easily manageable high blood pressure.

There is also hernias and weakness of the midline of the abdomen, called the Linea, Alba and ventral hernias. Inguinal hernias are common in PKD. And the red flags for young patients in PKD families that don’t have the diagnosis yet.

Urine tract infections are definitely common. Kidney stones are common about 25% of people. Having blood in the urine, rupturing a cyst are extremely common lifetime. Abdominal pain for different reasons, all of these above, you know, UTI, kidney stones, cysts rupture, all those things and also just because of the cyst burden extremely common. Headaches are common and palpitations too much of a prolapse are common. So these are kind of the early symptoms.

But then when you advance to more advanced kidney failure, then a whole bunch of things come into the picture that are not actually related to PKD, they're mostly related to kidney failure and the build-up of either fluid or, waste. So fatigue is very common. Nausea and lack of appetite is very common. Weight loss at the very end and feeling a metallic taste is comment.

Swelling is common. Sleepiness, all the way to coma, or being unresponsive. Trouble concentrating and focusing, itchiness, shortness of breath. Clora fusion, pericardial effusion.

High potassium levels which can lead to abnormal heart rhythm and cardiac arrest. Feeling cold, sleeping problems. Restless leg syndrome in young females, you know, not ovulating anymore, amenorrhea, which we called

cause of, basically, infertility could be there. Hiccups. Dry skin. Lower immunity. In general, muscle weakness, muscle cramps, bruising and because of mostly platelet dysfunction and neuropathy are also common.

Going individually over these things. (Poor audio)extremely common and late stages. Primarily due to build up of the toxins mostly urea. And sometimes also due to the very large kidneys and liver that are pushing against the stomach for the urea usually recommend low-protein diet.

And that basically gives you a little bit more time and but when it really becomes at the very end, only dialysis and kidney transplantation can fix that. If organ enlargement is the cause you can consider for liver enlargement, maybe octreotide.

Otherwise for a liver or kidney, cyst deroofing, or debulking surgery procedures could be considered, but again, you may your, at the very last stage of kidney failure, most of the times, it is toxin buildup is causing it. Not just the size of the kidney.

Anemia is very common in PKD in general. And at that advanced kidney disease, whether it is with PKD, or not with PKD.

There are two mechanisms. The first is iron deficiency. And a lot of people don’t have absolute iron deficiency. They do have iron, but don’t use it right. Absoline deficiency, when you don’t have any iron and it’s a loss of blood and it’s usually GI, or post operative or GYN losses. We recommend food rich in iron liver, beef, pork, chicken, eat lima beans, and kidney beans have a lot of iron or iron supplements, you know, could be there. But again, the functional iron deficiency, you don't actually have a deficit in iron, you just can’t incorporate it correctly into the red cells.

And a lot of times, you know, that absorption intestinal absorption of iron is a problem. And to, there's a patient, even if you put them on high dose they don’t absorb it correctly and incorporate it in the red cells and therefore IV iron infusions become very commonly needed at the late stage.

The other facet is the hormone that that I talked about it, erythropoietin. And this is a hormone that is made by the kidneys and stimulates the bone marrow to make basically hemoglobin in red cells.

And when GFR goes below 30, the levels of erythropoietin significantly drop and you can have anemia. Actually, PKD patients because they have higher baseline levels of erythropoietin, they actually develop anemia later than non-PKD kidney failure patients.

But you know, they typically get there at some point and the good news is that for about, you know, two decades now almost we have actually this hormone that is synthetic and we can give it to the patients without needing transfusions, and there are several forms of that and all of them can be given as subQ injections anywhere from once a week to once every month and that basically keeps them going without needing transplant, transfusions,

The metallic taste is a buildup of waste in the Blood and can also affect the bad breath. Patients usually say I have a foul taste in my mouth, almost like you're drinking iron, or you're eating iron. Often that

that indicates that you’re not too far from the point of dialysis.

And one of the very critical issues is high potassium, but again, you don't realize it until almost is too late because it affects the heart, and it basically can stop the heart.

So it really, that's why at the end of the kidney failure, we know at the end of the kidney life we check you know labs almost every month and we stay on top of the particularly potassium. We have many ways of lowering that, low potassium diet, you know, diuretics such as Lasix, kayexalate and also to other agents that are called been available for about three four years now.

(Poor audio) are also very helpful to manage those and by patients time before dialysis, the build-up of toxins and urea can also cause, you know, fluid around the heart and which is called pericardial effusion. And, the build-up of the fluid that we talked about in general pulmonary edema or also Leg Edema and diuretics can actually help with the fluid situation.

But usually, when you get to the point of pericardial effusion, you really need to get started on dialysis extremely quickly.

We usually don't sit on that.

And also for edema, if you can't get it out with the diuretics, then the only way out would be diuretics, dialysis, I'm sorry.

Now we know that when you have, you’re at the end stage and you have a buildup of urea and toxins, that can cause direct impact on brain and the nerve functioning. The usual things are sleepiness, confusion, and in extreme cases, coma really, but also some peripheral neuropathy have been reported in patients with kidney failure. Again before we had dialysis, the only thing we could do was to tell patients not to eat protein and if they protein levels and the urea levels or less than you know, you would basically buy yourself some time.

But again the issue with that is that you basically at the very end stage, you are getting malnourished by not eating. So again it comes to a point that we just say dialysis or transplant are needed.

Itching is also a matter of buildup of the waste. It aggravated if you have dry skin. Patients usually say it's not like a skin itch or anything. It's just right down to the bone. I had to get a brush and dig and my back was just bloody from scratching it so much The skin had broken out and I was itching and scratching a lot.

So that's also a common thing.

Now, the other things muscle weakness and muscle dysfunction in the end stage of the kidney disease. These are very common problems, you really don't want to wait to the point that you've lost muscle mass because very difficult to build up muscle mass on dialysis. We usually follow that carefully and me usually recommend either transplantation or dialysis before you get to that muscle wasting issue, but we know that patients with that vascular kidney disease, they have weaker muscles. They tend to waste muscle.

And also, if they are anemic, you know, the muscle functioning also get worse because you don't have enough hemoglobin. And if you have acidosis and the build-up of acidity, that worsens the muscle breakdown of muscle functioning.

So how do we manage that? We add basically sodium bicarbonate for the pH part and if the acidity is building up, we manage the iron. I'm usually tell people to exercise as much as they can and then dialysis initiations is the next stage, basically.

Now, the other a little bit more complex issue is that bone health, what we call kidney osteodystrophy, or bone marrow disorder.

We know that the key players are basically, the kidneys are critical to keep your bones healthy through how they actually manage calcium and phosphorus and vitamin D, phosphorus and PTH, or the parathyroid hormone that comes from four glands in your neck are basically main players, the contribution of the kidneys, they have been your get kidney failure, your vitamin D levels go even further down, a lot of people have vitamin D insufficiency anyways, but when you have kidney failure goes down.

Basically, when that happens, the PTH, parathyroid hormone starts acting up as a consequence and we need to slow down this process. So we add basically vitamin D or vitamin D analogs and we add, if the phosphorus goes up, we add binders, phosphorus finders, which are either containing calcium or other agents, such as sevelarmer, lantanum and iron.

And the point of that is really to keep this PTH and vitamin D situation and calcium and phosphorus at the target. And also buffering acidity sodium bicarbonate helps fit that.

These are just few pictures about, you know, what you can get with dry skin and it's called Xerosis, you know, but try asking basically, you have to use moisturizers and sometimes you'll be waxed balm can help.

This is a patient that has both a ventral hernia, so it's a midline weakness. You really see it when you start, you try to sit up because you are contracting your muscles. And here also umbilical hernia.

And this is an umbilical hernia in a child. This is in an adult so you can get big and can get even bigger than that.

So how do you treat the those? You know, you can, for a while, you can just put a girdle around it and it would hold it.

But if it's really bothersome and particularly if it's hot and you can't take that, take that you know, you can consider surgery with or without mesh, you know, to fix those hernias. For swelling and edema, you see, when you put your finger down and you can press for 15-20 seconds, that's what you see.

That's why we call it pitting edema, it is usually painless actually and people would say my legs would swell up by the end of the day typically and they say I remember a lot of swelling. My ankles, my ankles were so big, I couldn't get my shoes on my wedding ring did fit anymore.

My face was really puffy. So all these things are fluid and salt and water retention basically.

How do we deal with that? Mostly we recommend low-salt diet, but that goes on only for so much for so long. Duretics are really a common help typically Loop Diuretics, such as furosemide and Torsemide works in the early stages, but if you're on that on your close to dialysis and usually doesn't work anymore, you have to switch to one of these and also you know the compression socks and also letting, putting your feet up help with that in a chair.

Now in PKD, there are some issues at the very end stage, which is actually related more to the size of the organs. So you remember, you know, pretty much everybody would get kidney enlargement significantly by the end stage.

Some people also would have very large, liver not typically everybody.

This is probably 10% of people, but this is really very commonly for the kidneys. And these basic, you can actually compress and what I call in a real estate, cause real estate problems in your abdomen.

So how do we deal with that again? What, what happens when you have that compression? You can actually have acid reflux, you can have pain, you can have compression of the stomach and intestines, and can have shortness of breath.

You can have limitation of your mobility, bending, tying your shoes. Limitation of food intake and even in very severe cases, malnutrition. So we can manage in acid reflux with proton pump inhibitors, you know, Prilosec, members of those medications, and pain often needs pain management.

So it could be simple, you know, posture strategies or Tylenol or, you know, sometimes if it’s very severe, all the way to narcotics and eating more frequent meals, but less copious meal. So, instead of eating three big meals, have 6 or 6 a day small portion meals could help to keep your nutrition going at that point.

Now if you've done all of that and you have still again, a real estate problem that we need to debulk the kidneys, or sometimes the liver, cyst aspiration can work and we can put also medications inside of them to basically burn the inside, it's typically performed on a CT. The CAT scan guidance.

We usually for the kidneys, we only do this if they're only few cysts that are very large, they're more than three or four centimeters and they actually correlate to where the patient is hurting. Otherwise unfortunately, most patients with PKD in advanced stages have a lot of cysts, you can't do this.

Sometimes your surgical deroofing that they bring you basically open the envelope of the kidney and you chop off fifty, hundred, hundred fifty cyst. You know, at once, could help.

It was done extremely commonly in the 80s and let's say between 1975 and 2000. We are doing less of those because we know that it does not help at all to preserve your kidney function, if anything you're actually losing some good kidney tissue with that.

So it may cause persistent oozing of fluid after surgery, which is a big problem. And now we know that for kidneys, you know, Tolvaptan and is a good help to limit this size growth and somatostatin analogs like Octreotide, for liver enlargement could be considered.

Now, cardiovascular disease is a big problem in general CKD, but also in polycystic kidney disease.

Heart attacks, and strokes, and fatal irregular heartbeats are very common. The likelihood of having cardiovascular disease increases the more you go into stages of kidney disease, CKD four and five, definitely much higher. And then you're on dialysis, even higher than that.

You definitely need to pay more attention to settle things like chest pain, shortness of breath, palpitations, visual changes numbness, speech trouble, all those things are red flags for these and really go to the ER if any of those are happening because you're considered a high-risk patient for those things.

One recent development for patients who are on Tolvaptan, the question is when dialysis is it worth to keep that going? The original studies with Tolvaptan did not include anybody who had less than 30 of GFR.

So we didn't have really anybody was on dialysis, or been very close to it. But if we have now seven, eight years of post-marketing follow-up, from Europe, and Japan, and about three years in the United States, and we know that people can go down on Tolvaptan and reach much lower GFR, and I have patients that went all the way down to dialysis and transplantation on that.

And, my take is that, as long as it seems to be very safe to continue that. As long as the insurance companies are not saying we're not paying for it I would say you know it's safe and advantageous to still keep going on Tolvaptan.

Now this frequency of how often we need to see you in early PKD is really once or twice a year at the very most. When you get to stage three, its two to three times. Stage 4 is about four times, five times. When you get to really Stage 5 when you really need those injections of EPO for anemia and also in a checking for potassium it could be like monthly at that point. And my patients are very close every month that I see them. And you can see them even more often if, you know, they have pain, cyst rupture, blood pressure issues, headaches, urinary tract infections.

Now what about transplantation when do we need to talk about that?

Most transplant Centers do not want to see you until you hit 20 of GFR.

So 20% getting function, that's what they want. So again, when do you want to do it? Ideally somewhere, again between 10 and 15 percent, you know, for diabetics and maybe five and ten for non-diabetics.

So chance, on evaluation, you start that point and you get on the list.

And then at the same time, you know, you basically talk also about home hemo dialysis and peritoneal dialysis to have a back-up plan, if transplant doesn't work out.

And each of these have a specific axis that you need to get.

Transplantation is the best modality. It gives you the best quality of life and longevity is best done actually, if you never go on

dialysis and you get the pre-emptive transplantation, and you can get it either from a living donor, which lasts about an average 20 years now and or a deceased donor. The cadaver that lasts about 15 years.

You need the blood type match donor. And only the ABO matters. The +/- doesn’t matter. Really what matters is ABO tissue matches also required at the at the very end evaluation typically takes four to six months and you can be listed when you're below 20 of GFR.

When you get a transplant, the problems that the risk of infections and Cancers go up after that. S that's kind of the but again, overall is the best modality of, you know, replacement therapy.

Now hemodialysis, which is the blood type dialysis, that basically take your blood out of your system and we filter it is the most commonly used modality in the United States, but not in the world, in general, in Europe, in Australia, in New Zealand. They're almost at 50, 50, where about 88%, standard.

Typically is that hemo three times a week Monday, Wednesday, Friday or Tuesday, Thursday, Saturday. Each time is about three to four and a half hours depending on what your size is.

And honestly it prevent patients from working full time, they're already sick and they have to go to dialysis, almost three 1/2, a days a week.

There's also a slow hemodialysis machine. That's the next state machine that you can do at home. And the blood flow is much lower, is gentle. But you're doing it pretty much almost every day. I mean, usually five days a week all the way up to seven days. Again, you have to be able to do that for yourself. Because you don't have a nurse, you get the machine and you get trained and if you and two people are needed for that. So you have a second person so if something goes wrong you should be able to help you. And this is basically very good in the sense that if you eat or drink too much one day, you can take it off the same day and it actually lets you eat more healthy food. Then but again, you know, the insurance issues are there that you have to cover that modality and you have to be able to do it.

For hemo dialysis, you need vascular access. Either a fistula or a graft.

A fistula is basically to the connect, your her own artery, and vein. And the middle part grows as big as my finger and you can stick you. The graphs are basically when you put a piece of tubing in their arm when you don't have good enough vessels and basically looks like this.

So at the beginning, it's a barely a vein that you see and then it grows really big and you can stick that very easily. So that's for hemodialysis.

Peritoneal dialysis is the other modality. Basically use the membrane that surround the guts as a filter and we put water and sugar inside and then it goes there and sits around that membrane and the waste are filtered and it comes out, you can do it either manually with the bags in and out, or a machine can do it for you overnight.

You basically put eight ten liters of fluid and the Machine basically Cycles it in your belly and it takes it out on your done by the morning.

Definitely has the advantage of not depending on a dialysis machine as long as you have your machine at your bags, you can go anywhere. You can be on top of the mountains and still do it just need enough of those bags and the Machine. And usually family and patients are doing that. It needs a private room and storage room for supplies that are delivered once a month. Typically, the private room is really usually your bedroom because you're sleeping and it's done overnight.

Having pets could be a problem because infections of this cap. There are any issues. I usually recommend, not letting the pets, not having pets, or not letting the pets in that room that you're doing PD and it gives you full Independence, and you only see the doctor once a month for 30 minutes at a regular visit. Excellent for working patients and also you know patients have low blood pressure are the issues.

This is more gentle.

So the take-home messages is kidney (five minutes remaining) kidney failure causes nonspecific symptoms. Symptoms appear late in the course of the disease, especially stage, three, four and five, particularly. A close follow-up is needed, and you need to see the patient much more often.

Dialysis and kidney transplantation are the most effective ways of fixing, actually, that reduced kidney function and the symptoms of kidney failure.

This is my office at Emory University and we have a big team of all types of providers that can take care of PKD patients, and I'm open for any questions.

Thank you.

Okay, we have a few questions here. I'm going to try to read them real quick.

Does other urine properties such as frothiness, color, smell are they indicators of kidney failure? Besides urine volume.

That is a very good question. You know, people, when people get to the point of gradual, chronic kidney disease yet he urine volume is actually not that much less. Unless it’s very, very late in the game so you should not wait for seeing actually that you’re not peeing anymore.

That's a very bad sign.

You're not peeing anymore.

That's very bad.

So the urine volume is actually preserved for a long period of time, the other smell and frothiness and those things in polycystic kidney disease are not indicative of kidney failure, you cannot use those, you know, as a surrogate of kidney failure. A lot of times people are at the point of dialysis.

They're making a lot of urine even if they have swelling, but they're not clearing the waste and they're not getting rid of enough of salt and water. So but they're still making a good liter, liter and a half of urine every day without any problems.

That's really good to know.

Is there a kidney function decline curve for ARPKD? Is there anything similar to the Mayo prognostic for.

No, absolutely not.

We don't have a model, prognostic model for ARPKD.

What we’re realizing with ARPKD is that actually, we used to call this the childhood form of PKD. It’s not that show any more. There are a number of kids with ARPKD who make it actually make it to adulthood in pretty good shape. I have patients who are in their 30s and they still have normal kidney function with ARPKD.

So the game is changing. We always say ARPKD takes down the liver or the kidneys very early on by five, or six, or seven.

But we have not come up with a model that actually can predict where we going. And the reason for that is that the kidney enlargement is not there. The ARPKD. It’s there when you're born and for a little while, but the kidneys don't grow the way that ADPKD kidneys grow, that's why the kidney volume has been very strongly validated ADPKD. Not for ARPKD.

We're looking to that to see whether there are some other Imaging tricks that we can use to stratify. And basically predict how they ARPKD patients will do but we don't have a tool right now.

Is there any info on PKD causing hair loss or thinning, or Vision deterioration?

So hair loss is very common in advance, chronic kidney disease. The other kicker is actually the blood pressure medications that you have to watch for. A lot of the blood pressure medications that you know a lot of PKD patients are on can cause hair loss.

So, again advanced chronic kidney disease, whether it's PKD or not, can cause hair loss. PKD by itself doesn't do it.

Blood pressure medication can cause hair loss. And so those are really the typical take-home messages that I give on the hair loss issue. And then we also know that just aging causes hair loss.

That if your your 50s and 60s, particularly for males, you know, you a lot of males have that problem just by aging. But if it's really happening, really early, and there's nobody in your family on both sides that have has, you know, early hair loss then maybe you have to open up the chapter for other causes of hair loss and also in sometimes your thyroid function can cause that. Sometimes some mineral deficiencies, you know, zinc or things like that, can cause so you need a workup regardless of PKD or that issue.

Great, thank you.

Let's see.

Can you have peritoneal dialysis if part of your momentum is removed?

So that the general rules that if you want PD, if you want to do peritoneal dialysis the best patients are basically patients that have an intact abdomen.

No surgeries, no prior surgery, particularly on the intestines, and the membrane that's around it. So, a lot of times when you get into either a momentum, or colon, or stomach, if you’ve had a major surgery there, that membrane is not intact and it does not actually filter the blood very well.

And that's kind of really, usually the limitation for that. So I usually always ask, you know, the surgical history. Look at the abdomen. See how many scars they have.

Typically for instance, you know, C-section doesn't count against that because C-section is below the level of intestines and it only really involves, you know, the GYN area and very low. So that is not a problem.

But intestinal surgeries are usually a problem there.

Thank you.

So it looks like we've reached our deadlines. So there is a survey in the chat. If everyone would. Please take that. Sorry, we didn't get to all the questions, but I want to thank everyone for being here and thank you. Also, Dr. Rabhari, this was a wonderful presentation.