

Jessianna Seville: It's great to be here with everyone today, I'm not sure how many people are attending now. But I'm sure we'll have people now and later. And I'm really excited to talk about some simple steps you can use to leverage your lifestyle, your food, to really be able to impact your health. So, thank you so much for PKD connects for inviting me to be here. I'm going to give you just a little background, I got to make sure I it's a little bit of a different format and make sure I got my screen shared. And get me out of the way because we don't need that for sure.

Okay, so just a quick disclaimer, the material presented here, you see this on all of the slides. It is made available by PKD. Foundation for educational purposes only. This is not, you know, it's not intended to represent the only known necessarily best methods or procedures. It's meant to drive discussion help you guys find some more information. So please talk with your physician about specifics before you apply anything. And then disclosure on my side, I don't have any financial disclosures right now. I do own two organizations that impact PKD, both the Ren.Nu program, which is a nonprofit, and kidney nutrition Institute.

So quick, a little bit about me and I rewrote this bio about forty-five minutes before this presentation because I wanted to share with you a little bit about my story and passion for polycystic kidney disease. So, I'm both the owner and founder of Kidney Nutrition Institute and RenAlign and RenAlign houses the Ren.Nu program, which is a plant focused keto program. So, over the last three or four years, our group of dietitians have become really involved with PKD, I'll be really frank and honest, and I say this a lot, three or four years ago, I didn't know.

And really, I felt like I was a professional, you know, doing advanced therapies, top of my game, I didn't know how different PKD was from CKD. And that there really were a lot of amazing opportunities that were arising and amazing things for us to dig into. But it's just very, very

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different. And I'm really passionate about what we can do in the PKD community to improve the outcomes.

So, I really strongly believe in advancing the nutrition therapy, exploring new avenues if the current avenues aren't working. I think that it's exciting that there's new research and you know, whether or not you agree with ketogenic diets, of course, that's a very controversial topic. But it is good to explore where there might be an impact, and to be able to develop the science around it so that we can develop safe, effective therapies.

So, one of the things I'm really excited about is that we are taking some of that ketogenic research that people have so many questions about and we'll be engaging in a clinical trial with the University of Toronto in end of 2020 to 2023. So that's super exciting. And we're excited about that, because it can hopefully start answering questions like, “Are ketogenic diets really the way? Is there something else?” But there are lots of questions to answer. And so really, really, I feel privileged to be a part of that. And for the patients that work with us and the professionals that engage in this I feel like all of them are pioneers.

So today, we're going to talk about dietary strategies for polycystic kidney disease. These are really some starting points for you to think about. My goal today and I hope I can achieve this is that you guys get some real clarity on all the things that are mixing around in Facebook groups and things that are mixing around in Reddit and social media and online articles. The breadth of recommendations is crazy online. And I feel like a lot of people just want to know a few things to start with. I want to know what is actually going to really work and what is effective. So, I hope I can cover several of these things.

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Okay, so, let's talk about some top. So, I call these top seven dietary strategies. Number one, we're going to talk about simplifying sodium, I want to get a really good clarity on that.

Number two, fill up on fluid. And we'll talk about what that actually means. Manage, don't obsess over oxalates. A lot of questions about oxalates right now, and we want to just talk about what that can mean on a practical basis to me oxalates are like dietitian hell, because they are not exact, nothing is exact about them, and it can really drive you nuts. So just want to give some real clarity on what you think about when you're actually implementing this in your diet pick more plants, pick more plants, I know I said it twice. I'm cheating a little bit here. Carbohydrates and PKD. Get some clarity on this conversation about keto, not keto. And, or just carbohydrates. In general, there's lots and lots and lots of questions and confusions that are going on around this topic. And I want to bring some thoughts to the table and then get a plan for protein.

So, a couple things we think about. So, let's start about sodium. Most common recommendation in the whole kidney world is about controlling sodium. And being mindful of how much sodium we eat. Now, I'm going to start with this graph here.

And I want you to see where most people consume sodium in their diet. And you can see that 71% of most people's sodium intake in their diet is from processed or restaurant foods. 71% is from there only about what this is. 12% is what we get at home, whether it's like sprinkling on our food, adding it in our cooking, or other kind of wonder what this other category is, but it's such a small percentage.

So, when you look at, you know, bringing some reason, a reasonable conversation to this sodium table, you really want to think about where

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you're eating. If you're eating simple home meals, you're cooking yourself, embracing the beauty of food and how it fits in your life versus being on the run, eating out all the time, that can really impact how much salt you take. So, first thing this is a popular quote, we use it all the time. But “No sodium is not better than low sodium.” Anytime a person all of us do this get a chronic disease diagnosis, then what can I do? Doctor says you need to cut back on sodium. Because as humans, we want to do the best we can most of us default to he said cut back. So, I will do none, I will cut out I'm going to cut back and I'm going to cut out.

“No sodium is not better than low sodium” you need a little bit of sodium in your life. To be able to function correctly. There's a few case studies in the medical literature that actually show that low sodium really too low of sodium actually drove some people's potassium levels up. It's a really important electrolyte. And we see problems especially with how much people are hydrating with polycystic kidney disease with these very low sodium amounts, and people are getting headaches or feeling fatigue and not feeling well just because they just need a little bit more salt in their system.

For me, one of the common recommendations is we'll just talk about how are you using it at home, right? Maybe you've totally cut it out of all your cooking. And now you're not enjoying your food anymore, because it's bland and gross. That sort of thing. And maybe you can start adding it in a little bit.

Krystn Kuckelman: I'm sorry to interrupt, but my appointment didn't match the session. And we did start a little earlier. So, excuse me for that mistake.

Jessianna Seville: Do you want me to go back or what do you want me to do?

Krystn Kuckelman: I think let's just pause here.

Jessianna Seville: Okay.

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- Krystn Kuckelman: Since this is so important, and what you're saying, and we'll get started, we started on this piece. I'm so sorry about that.
- Jessianna Seville: No, that's okay. Do you want me to start back from like, the first piece not like the beginning-?
- Krystn Kuckelman: I think we can just pause it right here just like three minutes, and I'm so sorry. Excuse me I'm very-
- Jessianna Seville: No problem. It's okay if people can catch the extra at the end. Eleven to twelve then is that correct?
- Krystn Kuckelman: Yeah, I'm sorry. They-
- Jessianna Seville: No, it's okay.
- Krystn Kuckelman: I want it because I see people popping in at the end.
- Jessianna Seville: I was surprised why there are so few-
- Krystn Kuckelman: Me too. So that was my mistake. I'm so sorry about that.
- Jessianna Seville: That's okay. Hello, everyone-
- Krystn Kuckelman: I was so excited about the topic I decided to start early.
- Jessianna Seville: Be earlier dear or you miss out. Yeah, that's okay. Well, we'll back, I'll back up just one slide to do that we have.
- Krystn Kuckelman: Okay.
- Jessianna Seville: And then we can talk and for people that are popping in here, we'll back it up a little.
- Krystn Kuckelman: Just got too excited about the-

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Jessianna Seville: I know it's a great topic. Yeah.

Unknown speaker: This seems like a good place to start. Thank you.

Jessianna Seville: Yep.

Krystn Kuckelman: Everyone, I'm so sorry about jumping the gun on this. I was too excited. Lots of people popping in right now. So, we'll start exactly at the top of the hour as we were supposed to. We'll take questions at the forty-five-minute mark. And you can type those right in the chat.

All right, this is seeming more like, okay. So, we will start exactly at the top of the hour. Just in a few seconds, we'll take questions at the forty-five-minute mark. And we'll go ahead and resume the presentation again, my apologies. Okay, at the top of the hour, thank you so much. We'll get started.

Jessianna Seville: That's fine. Hey, everyone. We had, just for those of you that joined in, we got a little bit excited, and we started early. We're going to, we just backed up a little bit into the core topic. I want to just quickly introduce myself for some of you that are just popping in. My name is Jessianna Seville. I'm a registered dietitian. I'm also the owner and founder of Kidney Nutrition Institute. I am one of the main founders of RenAlign, which is a nonprofit that houses the Ren.Nu program that many people in the PKV world are familiar with.

I will just be really honest. And if you already were here at the beginning, I'm sorry that you have to hear this again. But three or four years ago, as I was, you know, very heavily engaged in private practice, and felt like I was top of the game in my expertise. I did not realize how different polycystic kidney disease was from chronic kidney disease.

To me, I have lumped them together, all ten, fifteen years in my career, and I never thought of them really as different other than, like, the kidneys look different. But in the last three to four years, one thing that has been really exciting for me, and very fulfilling as a professional is to be able to dive into understanding polycystic kidney disease. And coming to the realization that this is so different. It's such a different type of kidney disease.

There, of course, are crossovers between, you know, just supporting kidneys in general. But when you really want to get into good dietary strategies, you have to understand underlying mechanisms. And I think some of the research that is coming out is some of the most significant research, in my opinion, no offense to any researchers out there. But I really think some of the research on ketogenic diets and the progression mechanisms behind PKD is some of the most significant research that has happened in the last fifty years in kidney disease. And it's exciting, not because those are the end all solutions, but because it now gives us a pathway to look and look and look and figure out what's going to be the most safe, most effective strategy.

Okay, so I'm going to hold questions until the end, I tend to get really distracted by chats, and then I pause, and my brain just loses this place. I'm going to hold questions to the end. And we'll, I'll take questions at quarter two. If you have questions. Well, there are always tons of questions on this, please drop them in the chat. I will start with the oldest questions first. And we may we likely are not going to get through all the questions which I apologize for but that's just kind of usually how it goes because there's so many. Today what I want to talk about is I want to pull into some really core strategies that people can implement with polycystic kidney disease. There is some science behind many of them, I want to clarify some of the confusion that's out there. I think the breadth and controversy on nutrition is huge on the internet, everything from, you

know, the optimal ketogenic diet with a bajillion supplement and cleanse your body and everything else to like, don't do anything doesn't matter, except for cut back salt. And there's so much there for us to unpack.

And I truly believe that there are strategies that can make a big, big difference. And I want to give you some simplification to those, some clarity on those and a little bit of background on how we think about them. This is a quickly evolving field, and that is just so exciting for polycystic kidney disease.

I hope someone popped in my colleague, Diana, she texted me, someone popped into her session the other day, and they asked, you know, like, it was kind of a little bit of a snarky question. But like, "I bet you're so glad that you get to make money from BKD." And she's like, "You know, I hope that I get worked out of a job in five years." And that is how we feel too. It is a pleasure to dive into the research and come up with solutions. But I hope there is one soon for everyone.

Okay, let's talk about dietary strategies. There are seven that we use, that I think are really core. And I want to kind of dig into those. So, number one, simplify sodium. Number two, fill up on fluid. Number three, manage, don't obsess over oxalates. Oxalates truly are a dietitian hell because they are in exact, and I want to give you a little bit of perspective on them. So that you do not have to live in the rabbit hole of oxalates, which is like beyond confusing.

Pick more plants, pick more plants, and that we said it twice, right? It's that important. Get some clarity and carbohydrates. Obviously, we have a ketogenic program that we utilize. That is not the only way for every person. But I think that we need to be conscientious and understand the conversation around carbohydrates. And that's what I want to get clarity on. And then a plan for protein, which I think is really important too.

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So, let's talk about simplifying sodium. If you look at this graph here, what you're going to see is that more than 70% of most of the salt intake that people get is actually from restaurants and processed foods. That is a really, really important note to take.

Because when people are thinking about how can I simplify the dietary things I need to do, one of the most simple things that you can do is just bring your cooking back to home and be able to put a little space in your life for the experience of food, right? We're so busy. And we've gotten this mode in our modern day of like food being fast and on the table. And we forget the experience of actually enjoying the preparation process and our food itself.

Very little truly of our overall sodium intake comes from home cooking, unless it's hamburger helper type home cooking. So, one rule of sodium, 'no' is not better than 'low'. A lot of times when people are diagnosed with a chronic disease, and all of us do this, we asked what we can do. And then the next step is we're told like hey, for example, what you need to do is cut back on how much salt to eat. And what most of us hear is not cut back, we hear cut out. And so, on top of really high fluid intakes, a lot of times we're seeing people have places to kidney disease and chronic kidney disease, bring their sodium down super, super low.

We do need to have salt to be healthy. And there are some interesting case studies in the literature with people that are on these very, very restricted sodium diets and how it impacted actually elevated their potassium levels. And they needed to balance those electrolytes to get to the right place.

So, if you have been suffering through very, very bland food at home, you have cut it out completely. Perhaps, consider how it can fit in, in small amounts in your diet. For us, I'll give you a number here, but we

definitely don't do any less than fifteen hundred ever and we regularly see on people's logs like less than five hundred. Another really simple strategy when it comes to sodium is focusing on whole foods. So again, processed restaurant foods in the data shows more than 70%. That's where more than 70% of the sodium intake comes from.

So, when you focus on whole foods, meaning instead of pulling your rice from a box, let's say you're going to have rice for dinner, pulling your rice from a box and it has a seasoning mix in it, you make your rice from rice and then you add your own herbs into it. Or maybe you have fresh fruits and vegetables or if you haven't frozen and seasoned vegetables, but you're focusing on the original source of the food. Less processed foods can really cut back on sodium. For us, we also really love using garlic.

We love using lemon, vinegar, kelp seasoning, I'm a really big fan of, how come I just forgot her name. Her last name is Nosrat, and she wrote the book *Salt Fat Acid Heat*, where she talks about this flavoring of sour how it really can enhance our foods, we often will use that with a lower sodium diet to be able to really enhance your foods. If you've never added just a little bit of lemon or vinegar to a dish. See what happens when you do because it can really change the whole profile of a dish and expand the flavors that a lot of extra salt.

We have some people that like to use the kelp, or the seaweed seasonings are very, very low in sodium, but they give you that experience of a salt shaker. They also come with a really good mineral basis that we like.

Okay, let's talk about fluids. Now some of the research has definitely been showing right now that fluids are a very important part of polycystic kidney disease. Now, there are a lot of reasons for that. But for the most

part, we're aiming for our patients to about eighty to hundred ounces a day. Now with anything in health balance is the key here. So often again, us humans, we want to be proactive, we want to be the best and do the best we can. And sometimes, you know we missed the mark, we overshoot where we need to go, you don't have to do.

More is not always better when it comes to help. And when it comes to nutrients. And when it comes to fluid. We really believe that the primary fluid that's best really clean filtered water. That is our, you know, preferred water source.

Even tap water from some cities can actually be kind of salty, something to look into. We encourage all of our patients to eliminate soda and other juice drinks that have a lot of artificial or regular sweeteners. I just I don't think that there's any purpose to them other than once in a while as a treat. But the artificial sweeteners, well, they're not sugar, they can do some damage to your gut and the regular sweeteners are just going to be pumping your system full of sugar.

So as much as possible. cutting those down can be really, really helpful. People that need a little bit of flavor in their water. I really like right now the true lime or the true lemon little mini packets, they're very, very simple don't have any sugars like crystallized lime, crystallized lemon. And I think they have a grapefruit one and an orange one, it was a kind of nice to add in. Some people like to do mint leaves, or they'll do mint cucumber, and can make a really nice, flavored beverage without luck without a lot of added stuff, or colors or other things that they put in there.

The other thing that I like to point out here is remembering electrolytes. Again, what we see a lot of times is people are drinking a lot of fluid for polycystic kidney disease or Kezar on tolvaptan.

And then there's problems with headaches so they feel tired, or that sort of thing because they're just they've lost electrolytes, or they like to exercise a lot. And they don't focus on that electrolyte piece, they've cut their sodium back. So, whether it's adding a little bit of sodium into the MEK mix, maybe getting some mineral drops, but remember that you still need those electrolytes to balance out that huge amount of fluid. So really important piece.

I do think that this needs to be individualized. We've had some people that they've heard the three liters a day magic number and that's what they aim for. And they just don't feel good. There. And so we are just back it up just a little bit to where we get at a comfortable level and balance those electrolytes as clinicians, I know looking at the labs looking at their dietary intake and they feel so much better. So, so much better. You can definitely over hydrate in some situations, although this is really an important strategy for dilution of you know, the oxalate crystals, it's important just for how it drives some of the pathways that are involved with PKD progression. More is not always better.

Alright, let's talk about oxalates. Here you'll see we don't say eat a little oxalate diet. We say, "Manage, don't obsess over oxalates." Oxalic management falls into three basic steps. From what we know right now I think there's actually maybe a fourth one in there. But number one is that you need, obviously, the quantity that you intake can make a difference.

But let's say you eat, we'll use the most common high oxalate, food, almonds. You eat a bunch of almonds goes down in your stomach get chewed up, and that goes in your gut. And what happens there is that the oxalates are, you know, your food starting to get broken down the oxalates in your gut combined with calcium oxalates and calcium bound together would be excreted in your feces, excess oxalates would then be absorbed into your bloodstream and then go into your urine. So the first

step is capture some of the oxalates in your stomach with calcium. The second thing is balancing out and we'll talk a little bit more about this balancing out the pH of your urine when it comes to, so you don't get oxalate crystallization and then eliminating them.

There are also some preliminary sciences that gut probably really impacts oxygen intake. So, let's talk about some of the big the big ones out there. Spinach, almonds, beets are some of the really, really big ones we see. A lot of people are like, I've been like, you know, really focusing on my health doing a green smoothie every day, and they're getting tons and tons of spinach, or they're like, "I'm going to do a ketogenic diet." And I'll tell you tons of the process, probably almost all of the ketogenic, processed food out there, the bars, the bites, then flowers, everything already with almonds. And so, they're putting in a ton of almonds into their body. And then beads shows up in a lot of powder and that sort of thing.

So again, the, the theory behind Oxalic management, is that what they were seeing in the research, here's a tubule in the kidney, right? The urine goes through this little tube here. What they're seeing is that you can leave little tiny micro crystals, calcium and oxalate binding together, not in the gut, where it can go out in the feces, but it was binding in the urine, and these little crystals becoming lodged in the tubules. And then to flush them out, the two will have to expand and that expansion of the tubule is what is thought to be driving this activation of his mTOR step three process for this, you know, assists grow.

So, backing that up, if you can eliminate crystal formation, which can come down to not having the oxalates to go in there to begin with, and having the right pH in your urine. So, you don't get this crystallization of this calcium and oxalate making these little micro crystals, then you could impact the progression of your polycystic kidney disease. Eliminating oxalates is not in and of itself going to shrink cysts that we

see in some of the other, you know, emerging science, but it can help prevent progression, which I think is a really, you know, on my side, I almost think like why not like why not just swap out some of those foods

So, again, on the oxalate management, calcium, really important piece, get some calcium, or magnesium or other minerals in your gut to bind with that calcium or that bind with the oxalates and get excreted in your feces. Number two, get some citrate on board, you can lemons, there's other products out there that you can utilize as well. And then hydrate so that your urine is dilute. This is generally the easiest one for most people because they're hydrating, like crazy for polycystic kidney disease anyway, so that's kind of your Oxalic management Strategy.

When it comes to find me lists online, how do I know which foods are high and low in oxalates? There's like a bajillion of them out there. And they can get really scary because they'll say, hey, like this one is red, and it's very high and don't eat it. ever, never, ever. So, people keep eliminating food after food, after food. The thing that makes oxalates tricky is that number one, it's really an inexact science, you can have the same food grown into different locations, and they'll have a totally different chocolate count in them.

So, we kind of get in a good ballpark for us, we aim four to give it perspective around hundred milligrams a day. And that helps us look at a food, for example, cashews, and we say well, like cashews, or like, I think they're fifty milligrams for a serving. We say a lot less about half of how much about I should eat in the day.

So, I'm going to have some cashews, probably 100% want to get some calcium on board with that. Or maybe there's something a little bit better. So, it's not quite as much like the columns *[Unclear]* *[00:55:01]* which I think are about twelve milligrams. So, my aim for some of those lower

ones doesn't mean to ever have the high ones. But it needs to be really, I'd need to start understanding about how they're going to fit in that oscillate budget. I think there's going to continue to be some emerging science on here with the gut, like the guts of an important part of oxalic management as well. But we don't have enough, you know, application strategies right now on that.

Okay, let's talk about plants. Now plants are really important because they're alkaline. So, you remember me talking about the pH and of the urine when it came to oxalate management. Plants really help alkalize the blood and help us alkalize the urine and that's a really simple *[Unclear]* *[00:55:46]* not just for polycystic kidney disease, but for chronic kidney disease too.

So, including plants in your diet is so incredibly powerful, not to mention the amazing amount of nutrients that they hold that nourishes our body, and helps our body chemistry, work and function and keep rolling along. So, picking more plants is very important. It's ahead of me, they're full of nutrients. I can't say that enough. I'm going to just go through a couple plants that we really love.

There's more than this. But it's really nice to start seeing some foods that you can have while there's discussion about what you can't, but we love cauliflower. Works great for people that are doing lower carb ketogenic diets also amazing roasted in my opinion. We love cucumbers, we love the kale, and the colors can be really great. We'll say a tip on this because I think kale can get kind of dry is that if you'll just massage it or rub it a little bit if you're going to make a big kale salad can really soften up those tough fibers and make it a little bit less chewy.

As it were, we love onions we love pretty much all of the salads, the squashes, if you're a gardener, squashes are going to be coming on if

they're already not in my garden, because I'm not great gardener but and I'm in like the Florida and it just rose things like that right now. But this is something that will be coming on for a lot of people and you could utilize that a lot of great ways to use the squashes, whether you're making the zoodles you're going to sauté them up.

A lot of great things you can do. We love peppers, we love broccoli. We love greens like arugula. So, a lot of good things you can do there. Okay, let's back this up a little bit. We're talking about carbohydrates and polycystic kidney disease, the hottest, most controversial topic in the PKD world, right now, let's talk a little bit about some of the science that came out of the WHIMS lab, and what it means, and then how you can think about how carbohydrates are going to fit into your diet.

So, most of us function on glucose as our body's fuel, that's what helps drive the cells. Our bodies can very successfully function on something called ketones, as well. So, ketones and fatty acids, our body utilizes them when we don't have enough glucose, it's kind of the secondary fuel source. But our bodies can function very, very well on ketosis as well, your cells are going to react to it just a little bit differently.

So, in the WHIMS lab research, what they saw in the animal models, and again, like, we all know, right, these were animal models, so you need to have a clinical trial in humans. But this is like such important science to think about the pathway in the animal models. What they saw is that when glucose was taken away as a primary fuel source in the body, and our body converted to using more ketones, that they saw that the cysts that there was this inhibition of the cysts, so the cysts really feed on that sugar and feed on the carbs. And when you take that away, and it's not available, our bodies can still function on ketones. But the cysts can't grow anymore, because they don't have that glucose.

Now, this research went through a couple different layers. And this is why there's different things that come out in the conversations now. So, at first, you know, the rats were given, you know, hypo caloric diets, meaning just really low-calorie diets. And they saw that there was a difference.

And then the smart researchers, doctors, Dr. Wines, the people in his labs, they looked at, okay, well, why? Why did the hypercaloric diets make a difference for PKB. And they noticed that the animals were eating all the food in one sitting. So, then they tried fasting, time restricted feeding. If the rats fast, and only once a day, what would happen? And they again, saw that there was an impact with the cyst growth.

So, they thought, well, maybe the rats are getting into ketosis over that fasting period. So, they tried ketogenic diets, again, they saw that there was an impact. And I'm like, what part of ketogenic diets make a difference? And that's when they tested beta hydroxy butyrate, which our body naturally produces in ketosis. And they saw again that that makes a difference.

So, do you have to do all those things to get an impact for yourself? No, you don't. The core function right now as we understand it, is being able to produce some sort of beta hydroxy butyrate on the most simplistic cell scale, but also being able to reduce carbohydrates in the diet. I think has a lot of merit. Also utilizing up that glucose in our body with exercise I think can also be really impactful.

So, let's look at what this looks like on an intervention strategy. Again, I need to preface this that there's not human studies on this. Is it a high-risk activity to engage in lower carbohydrates or ketogenic diets, a lot of debate about ketosis, I don't think that there's really any debate? Cutting

back on carbs can be helpful. Fasting for many, many people can be done very safely and very effectively. There's some sometimes for women, they need to be careful with their hormones, but a lot of people can be successful.

So, let's talk about a low carb or ketogenic diet. This is the older side. So, a ketogenic diet is actually 70 to 75% fat, a low carb diet would be starting to eliminate some of the core fiber foods and bulking out with some vegetables. And using a little bit heavy on your fat, you're not going to be aiming for your body to actually be in ketosis, but you would be cutting back on the amount of glucose available that could feed those cells.

The amount of protein getting another controversial topic really depends on the stage of kidney disease, it's not the same for every single person. So often, what we equate in our mind is that if I go low carb, I have to go high protein, really high protein for later stage of kidney disease is going to knock your kidneys out like that, because our kidneys can't process that level of load. If you have a little bit more kidney function, you might be able to manage more, but I don't believe a high protein diet, for anyone that has some kidney dysfunction is going to be helpful.

But you can start focusing on healthy fats in your diet, whether that's olive oil, or avocados, or you know, making sure that you just have a good you know, a good amount of fat with your meal. We use coconut, we use tahini we use. Just blinking we'll use a little bit of mayo, pesto like these are some good fat sources. Olives are really amazing as well.

I think for people that are wanting to shift to a low carb and definitely to a ketogenic diet, that some monitoring some medical monitoring and some advice is incredibly helpful to make sure you know what you're

actually aiming for. And, you know, like, what is the lifelong plan with this, like, what is this actually going to mean?

But other things that we see, for people that are starting to shift into ketogenic or these high fat diets, some people don't tolerate fat well. And so, if you're not sure how you're going to tolerate it, it's a good idea to do one or two very high fat meals, ketogenic meals, maybe we're not aiming for ketosis, and see how you feel with those meals. Of course, there's lots of strategies to use to tolerate fat better.

But you could, you would want to work with a professional on those, but it is definitely I think there's a lot of I think, for all of us whether or not we have polycystic kidney disease, there is some benefit to being really considerate of what kind of carbohydrates we're putting in our body, especially with the simple sugars, like even if there's one thing that you could do is, you know, eliminate more the sugar in our diet or diets are so heavy and sugar in America, that can make a massive impact for you and your health.

Okay, a little bit about fasting, fasting slash time restricted feeding. So, this can be a lifestyle to try while the people love it. Once they get past the first two to three days, we usually have our patients they're not used to, and this is describing more time restricted feeding. And if they're not used to having this gap of time without food, maybe they like always eat dinner at 6pm then they always have a snack at nine and eleven. And they wake up and have breakfast at seven. They're not used to having a gap of time where they get just rest. We'll start with twelve hours and then we'll you know, expand it out by to one to two hours every week to about sixteen to eighteen hours a day.

One thing that I've noticed a lot in some of the PKD groups I follow is there seems to be this glorification of longer fasts. And I just I wary of

that because I don't think we want to rob Peter to pay Paul. And so be careful of starve these, starvation trends that we mask is fasting, long, extended fasting periods are not always the healthiest thing to do. You do the nutrients in your body to be healthy and to be able to you know all your functions to run so I think nourishment is a better goal than just fasting and you can nourish yourself really well, even when you're doing time restricted feeding or fasting.

I'm going to back this one up just so, but it makes her unclear. For some people trying to ketogenic diet can be a great strategy. Some of the emerging anecdotal research is showing that people have an impact, it does not mean that that's the only thing to do. And that you can get an impact from doing other pieces.

If you're in a space in your life where you want to try that I do think that you should work with a professional. There are, you know, different professionals, we do a training program for them. And we did quite a bit for you in ourselves, understand and learn how to do this safely. But you can look for professionals that have experience with lower carbohydrate or ketogenic diets for PKD does take some professional training to do it safely and accurately for patients.

But that can be an option for some people, there is some you know, people always worried about their lipid levels. And that in and of itself is another conversation, but ketogenic diets in and of themselves are not going to cause cardiac disease in, in my professional opinion.

Fasting, I feel like a lot of people can try that if you have lots of hormone imbalances as a woman, maybe just start really slow with this and make sure you're nurturing and nourishing yourself really well in your eating period with high quality nutrient dense foods. Okay, let's talk about protein to another controversial topic ketogenic diets and protein have so

much debate this one patient forums in particular, within the professional community, it is, you know, pretty accepted in the kidney world that a lower protein diet is better.

Some of the research has not shown that a significant protein restriction for higher stage PKT makes any sort of a difference. Later stages, I think you just still have to consider the function level of the kidney and how much it can handle. So, what should you do? Should you be vegan? Can you have meat? Can you have eggs? Can you have dairy? You know what is going to be your plan on protein, there is a lot of benefits of learning to move more plant forward in your food choices.

There, you know, meat can fit in some people's diets think you want to remember it can also drive a little bit of those higher uric acid levels and higher alkaline or higher acidity in your urine. But it can have a place and a lot of people's diets. It's a good idea to know what your target is going to be personally popular diets like bulletproof are really quite high in protein in my opinion. 1.5 To 1.7 grams per kilogram or we're aiming more for a normalization of protein like point eight to one grams per kilogram.

Some people have a little bit more wiggle room and some people don't. If your kidney diseases later stage you're going to want to be especially mindful. Oops, sorry, of how much protein you have. I think eggs can be a great option for a lot of people we use fish love that fatty fish for the extra fat.

For some people are not doing ketogenic diets, you can fit lagoons in your diet, which can be great. Some of the brands of tofu are not high in oxalates. And so that can be a good option if you'd like tofu. Not for everyone, but a lot of people like it. Some dairies not everyone, not everyone tolerates dairy, but you know a really good quality dairy can fit

in a lot of people's diets as well. A couple of our favorite foods that we use regularly in our nutrition plan can be eggs and pepitas, blackberries, clementines, coconut products. We love salmon, and the lemons and limes or citrus, radishes, olives, avocado, those are some really big ones that we love. Whoa, hold on a second, we're getting ahead of ourselves.

So, hopefully you see there's lots of beautiful colorful foods that you can have all of these in their own way are full of nutrients and very nutrient dense. Okay, so let's just talk about, you know, a couple practical skills on how you can bring all of this back home. So that's kind of a dietary structure overview. If you're feeling overwhelmed, you're like, well, that's a like six things for me to do.

Because I wrote seven but two of them were add more plants. Just pick one, right pick one you've probably already mastered sodium a lot of people have so maybe pick the other another one adding more plants in your diet. How can I get you know more vegetables at lunch and dinner or even breakfast? I'm going to put vegetables at breakfast. A lot of countries vegetables for breakfast is great.

So, let's talk about building a PKT friendly meal. So first, choose your vegetables or fruit, choose some healthy fats and then choose a protein. I think you can prioritize plant proteins over other proteins. Most of us when we're thinking about, "Hey, what am I going to eat?" We automatically default to actually number three first. Oh, I'm going to have chicken, I'm going to have eggs. Like we're building backwards. If you want to choose your vegetable or fruit first, what vegetable I'm going to include in this meal today.

What do I love to torture myself with vegetables? What do I really love. Broccoli is my favorite salads, my favorite. You know, these are my

favorite, whatever everyone has their own vegetable, that is their favorite corn is not a vegetable, just as a side note.

So again, salad, choose some really healthy fats. If you're making a salad, that would be a good dressing with a lot of olive oil, maybe some avocados and nuts and seeds, and then choose a plant protein. This is an example of tofu, which could be it could also be cheese. I'm sure it can. Also, I don't know what else it could look like marshmallows. But marshmallows isn't a protein. So that's not marshmallows.

This is an example of like an amazing meal that we think would be really nourishing for a lot of people you can see it's got some good nuts and seeds in there. And deep greens just squid you use that. Mime over the top really good, beautiful balanced meal, tons of nutrients in it. Not mean obviously, if anyone's table looks like this, when they eat, someone's got a lot of stuff to clean up. But that is a beautiful, a beautiful, beautiful meal.

We do we love to do soups, we love to do salmon dishes with vegetables, several the people we work with, they just really like the simplicity of like salmon with a vegetable that works really good for them. But really emphasizing that plant piece is really, really powerful.

So how do you create a meal plan and we get a lot of requests for can you just create I just need a meal plan like just give me a meal plan. And I'll just do that because I just want to know that I'm safe and everything's going to be okay. I just did a quick example here. But if you really want to get a handle on putting food and nourishing food into your life, dedicate a little bit of time weekly, honestly, probably only maybe ten to fifteen minutes. Most people have breakfast and lunches that are kind of go twos for them, they use them regularly. If you don't then just start with one meal, right? What's going to be kind of a couple of go to breakfast

that I really liked and focus on learning what that is whether it's cooking it or you know, whatever type of food that you're going to be using.

But kind of get in the mode of this is always my breakfast, and I really liked doing this for lunch and then can I try different things for dinner? Or can I try different things for lunch? List out your meals is a good idea, right?

So, I know that we're going to do you know for Monday have salmon for Tuesday we're going to do like in our house, we call them super salads. We do salad and then we get a bunch of toppings everyone makes their own. Wednesday we're going to do tacos and Thursday and Fridays. I'm not cooking anymore that week.

So, eat our taco leftovers and we'll might be taco salad a different night and then get a good critic grocery list format and use your left over's that can be really, really powerful quick example here, though, of what this might look like on a more ketogenic type of approach. You know, cheesy cauliflower grits, coconut yogurt, parfait, flax bread, hummus, avocado sandwich, I think there's something else here on the side. I can't see it. Maybe some fat bombs and then this one pan cheat meals can be really awesome.

Hey, grocery shopping tips. It doesn't have to be simple. It doesn't have to be expensive. Keep it simple and whole foods focused. The more that you are using processed foods, the more that your bill honestly will go up. The internet is so powerful and so helpful for finding just some simple recipes if you're like man, I cucumbers are my favorite, what are like ten great cucumber recipes and then you can cook one of those this week, get some good quality calcium sources in good quality you know, maybe that is a yogurt or a little bit of the sesame seeds. If you don't tolerate dairy that can be another good choice.

Avoid the processed and sugary foods. Look for those hidden sugars. They are like everywhere. Read your labels for sodium. Sometimes all you do is just swap products and you'll get way less sodium. A common one will receive people caught on the sodium and maybe it's not a big deal if you're not eating out a lot would be salad dressings.

One of our hacks is that we might we take a salad dressing that we like I've really, really liked the primal kitchen or the So I'm going to forget the other brand. I think it's 'Enjoy Life', but they use avocado oil as their base. So, Kensington are pretty good. And I'll use a little bit of that. And then I'll put extra olive oil on top for that extra good healthy fat boost. I really liked the California brand of olive oil; it's got a pretty high polyphenol count.

Okay, so everyone can start. By doing just spending a little bit of time cooking something new, every single one of us can put food back in a place where we view it as nourishment, and something that can come into our life. Even if you hate cooking. You can find simple foods that you can bring to the table that don't need a ton of preparation. Maybe it's you know, blackberries, no need to do anything other than wash them. Salads are about as easy as you can get. And those can be some really simple things.

Okay, so quick action steps and then we'll move into questions. I see nineteen new messages in the chat. And that's a lot of questions. So, a couple clarifying simplify sodium. Remember, no is not better than low, you can have a little bit if you're tracking in a food blog, you might aim for around, you know, fifteen hundred to twenty-three hundred milligrams a day. People that are doing more ketogenic approaches, they might need a little bit more because that can be you definitely lose a lot of sodium and ketosis Fill up on fluids manage, don't obsess over oxalates if you can at least identify spinach and almonds in your diet and

beets, just like those three big ones. That is a great place to start and start including some calcium sources with your meal, pick more plants, carbohydrates can be very helpful, get a good plan for protein. And then I think that that is those are some really, really huge pieces and I think copied and pasted this line in here. But the concept here is that you want to prioritize getting this the prioritize doing a little bit of meal planning every week.

You'll see if you just tackle one meal at a time practice lunch, dinner, snacks, looking for options, some of the websites online that you can be able to find a lot of solutions for us as dietitians this beyond dietitians I hate meal planning. But for us, we work with people with PKD I feel like it is such like a great learning experience to sit down and actually talk about what we're going to eat not vague principles like sodium, but like, what does our breakfast going to look like. And like, let's think through this together and really learn it together so you can be the champion of your own health.

Okay, from ADPKD, of course you can get on that registry. And then I would love to take questions right now, I'm going to pull up the chat. I'm a little bit scared because that were twenty-four. But I will do my best to get through them as quickly as I can. And I hope I didn't talk too fast. I tend to talk kind of fast.

Okay, questions about, "Fluids or the sparkling waters that are no sweeteners, sugar and zero calories? Do you feel this is equal to clean water?" So, if you're just talking about like seltzer type waters, or just where they just added carbonation, I think that those can work for a lot of people. I mean, I just think like real water is obviously the best, but you can include that for sure.

“Is it okay to use citric acid as a salt substitute rather than kelp?” That's a good question. I haven't used that in my food. But I don't see any reason why you couldn't put a little bit of citric acid on your food. I had one patient where they didn't want to do so many lemons in their diets. They bought like a five pound; they were both scientists too. But they bought a five-pound bag of citric acid to use in their daily life and that's what they did.

So, let's see. “Can I have one cup of hot cocoa or a smoothie with cocoa nibs once a month on my period? I used to drink cocoa three times a day.” That's a really, really specific questions. Really specific questions on that how I fit in this favorite food in my diet are great to talk through with a dietitian on your individual case. It's you know so much again is about that balance so there's usually a place to fit every single thing and I had one patient and he really started missing pancakes and he went through like all he was doing a ketogenic approach he just really missed pancakes but all the mixes were, had almonds in him and he's like I just did it like I just had pancakes like once or twice a month and I love that and he did really good calcium source and probably will not perfect choice but perfection doesn't equal progress.

And that worked for him for you know a plan to kind of include pancakes. I see we have another gardener into the in the mix I could probably learn a lot for me my gardens a bit sad. “Can you restate the reason that oxalates are problematic and PKD in the most simplistic sense?” Oxalates are a problem for PKD because they create micro crystals in your urine.

And in the research right now, what they believe is that those micro crystals cause the kidney tubules to expand and that kidney tubule expansion drives, it activates some pathways and that drives cyst growth. And that is why there are potentially some problems with oxalates.

Oxalates are again an emerging science, not even just in PKD, because there's a really strong tie to the gut. And that is not totally fleshed out. So as kind of a, I guess you'd say a safety-first type of strategy, as we're exploring this is that we've pulled down to a, you know, an excellent managed diet.

Where do you find PKT focus nutritionists? If you are, there's a couple places that you can look at Santa Barbara nutrients that makes keto citric, they have a database on their website. I don't have a financial affiliation with them. But we do collaborate closely because they're both really interested in ketosis and how that's going to improve people's nutrition with PKD.

They have a good database on there. The other thing is that you can go to National Kidney Foundation. I think it's, CKDRD. or no it's kidney.org/ckdrd there's a long list of renal dieticians on there, they are not all PKD specific, there's a really small amount. But if you find someone local that you jive with, and you want to work with, you can ask if they'd be willing to get more training.

And it also depends what angle you're going to be taking on it. You can also ask if they're familiar with polycystic kidney disease, and then, you know, you're hiring them. So, if they say I don't do ketogenic diets, and that's what you want to do, you might need to find someone else or say, "Would you be willing to learn? Can we work on this together?" I know my group, we mentor, many dietitians, they have their own patients, and we just mentored them through their patients, and they train through us and they pass on some of that initial training on to their patients. "What is your view on dairy products? What should we aim for?" This is a good question. It's really very different for some people, there's quite a lot of dairy sensitivity, I've noticed. But if you don't have one, then I generally aim for a dairy source with most meals, because it has that

calcium to bind up the oxalates in the food. And I think that can work for a lot of people. I do think that you should focus on the quality dairy products that don't have so many hormones in them. But I mean, that's a slight personal opinion.

“How often should you fast in a week?” Again, this is a really individualized decision based on your overall strategy. Different people have different goals with fasting, some people like to do it every single day, it just becomes part of their regular routine. Some people will do, like if they're going to do actual intermittent fasting, they'll have like one day a week that they would fast or, you know, some people will do it once a month. So, it's just really, really different.

“Does a keto diet negatively affect someone who also has heart disease?” Thank you for asking this question. Keto diets high fat, and traditionally, we have always thought high fat diets lead to heart disease, right? That's called the fat heart hypothesis is a hypothesis. It's really interesting, just sort of my perspective, we also deal with a lot of very plant-based diets. We have used vegan diets a lot in our practice as well.

And if you look at the ketogenic community and the vegan community, and we engage in both, both of them say the exact same things is that it helps heart disease helps heart disease, and both groups are getting an impact from it. So no, I don't think a ketogenic diet in and of itself is going to drive towards a bad outcome for heart disease.

I do think you need to be smart with what kind of fat you use. And there are some people who are genetically predisposed to not tolerate their fat well, and in some cases, a ketogenic diet is not going to be the best for them. We have people on the other hand, who they move into a ketogenic diet and their lipid profile gets better. It just gets better. You just have to understand that the first especially ninety days or so into a ketogenic diet,

everyone's lipids go up and then they kind of go down and stabilize, or almost everyone.

“Was told to stay away from saturated fat, isn't coconut high in saturated fat can speak to that a bit?” Thank you. Good question also. So again, another very, very controversial questions surrounding saturated fat in and of itself. We use coconut quite a bit and we have people with great. I mean, if we were going to tie fat to lipids with great lipid profiles, I think that it has a place for a lot of people.

That being said, on like an advanced practice, we engage in nutrigenomics and some people genetically don't process some of the plant sterols and they also don't process some of those saturated fats very well. And it's not across the board, you can't say across the board, humans who eat saturated fat are going to get heart disease. Not true and honestly, has not really been proven with great research.

However, there are some people where that could be a risk. And so, you know, as you incorporate it, you're going to watch your labs and see kind of where you fall. Fat in and of itself is not exclusive of fiber, you need a high fiber diet really, in my opinion, help balance some of that fat. “Okay, what about tomatoes? Should there be limited to they be limited.

So, tomatoes, and a lot of foods. When you look on the internet and you're like best diet for kidney disease, you'll see health line mail health couple other websites pop up first, and what they'll have on there is top ten to fifteen foods to avoid if you have kidney disease, and then the list out things like tomatoes, potatoes, oranges, all these different things. That information is just straight up an accurate, what they are basing most of these lists on our antiquated perceptions that a quote unquote renal diet is a low potassium, low phosphorus, low sodium diet, like package it all up in a little box. That's not necessarily true that the new science shows that

potassium is geared for people. Tomatoes typically end up on a list of like donate, because they're considered a higher potassium food. But a lot of people have wiggle room with potassium. It's very individualized. Some people can fit tomatoes in just fine in their diet.

Okay, let's see, "Is there a recipe on Ren.Nu for coconut, vanilla fat bombs?" I don't, I don't know, to tell you the truth. But you could just I think you could just Google it. And you could find a pretty good one. I mean, in the actual Ren.Nu program, yes, we have a ton of recipes that our participants utilize, and it is in there, the on the website as a freebie. I can't remember if it's in the download, there's a free download on the website, a three-day meal plan that has a ton of recipes on it. I can't remember it's in there. I don't think it is. I think the Blackberry Bliss bombs are my favorite that are on there, though.

Let's see, "I avoid soy altogether due to my polycystic liver disease that most PKD patients have too many plant hormones negatively interfere with estrogen. Is this information still accurate? This is a good, good question that we have addressed many times.

Actually, explored this with a hormone specialist because they get nervous through like to use flax. And, you know, estrogen metabolism in and of itself, just like oxalates is not a straight line into intake equals output of estrogen metabolism comes down to a lot how your liver functions that comes down to your gut health.

So, I don't think that you can exclusively say that soy is going to drive a rise in estrogen and drive, you know, liver cysts. That being said, I also don't know if there's a ton of research in that area.

If you're happy without soy, then it's you know, I probably would just exclude it if you need to fit it in here and there. It can be fine as well. I don't I just don't think that there's a lot of exactness I just know in

hormone metabolism itself. It is not a straight line as eliminating flax or eliminating soy. Even some of the hormone specialists. Don't always do that. But some people I also just anecdotally, they've noticed that they feel better that way “Do you need to have your liver panel done every six weeks by your nephrologist to do keto with polycystic liver disease No, you don't. And we don't have anybody do that.

“FYC for the heart disease question. I have a client who had a triple bypass whole food ketogenic diet for a year doing very well.” And so, Aaron dropped in a link here. Thanks, Aaron. Aaron's is a nutritionist in Switzerland, and she is amazing. She is She is really amazing. Thanks for dropping in that article, Aaron.

Lisa, “What are the best keto low oxalate plant proteins?” Wow, this is a great, a really good broad question. I will say in our meal plans, we do use tofu. We use some nuts and seeds really like pitas. We like to use some of the yogurts and some I mean, yogurt and cheese is not a plant based one, but we'll use them as a non-neat option as well. But on plant proteins with primarily are leaning towards like if they're heavy on a protein, more either a tofu or a seed or nut butter type protein. It's hard on a ketogenic diet to include a lot of lagoons, which is the other default on the protein. And we just we don't do as many because people would rather use their carbs somewhere else. And even though beans are good, but that's not their first choice.

“I cannot have dairy”- what? We got five minutes, right? Okay. Cool. Thank you. For that reminder, we'll tie things up here in a little bit. “What plant based dairy substitute? Do you recommend we have a lot of people that like flax milk If you're looking for milk, we have a lot of people like coconut yogurt? If you're looking for yogurt, just watch for those sneaky little phosphate additives. They put in the coconut yogurt, our whey protein shakes, okay, very individualized for the person and

how much protein they're at. So, people can fit that in. Let's see, I already started, I already answered about finding a nutrition specialist who's focused in PKD.

So again, you can go to sandbar nutrients. I group is obviously PKD specialists, but there otherwise, you just need to ask them, right? Call them in your area, look at the NKF website. Do you work with people with PKD? And then you need to follow up with what they do if they're doing a conventional renal diet. That may be not what you want to do. There's a really broad spectrum of how people are practicing with PKD. And so, you know, again, you're hiring them, you drive the ship, what do you want to achieve?

And what outcome do you want? What protein sources high in acid? Meat. But I'm not anti-meat. A lot of times it gets mixed up because we promote a plant focus ketogenic approach, we utilize that in our practice, that it's vegan keto, and like meats against our rules. And that is not true. We utilize it. I mean, just in our core protocol that we started with, we use eggs and fish. And we have, you know, started looking at adding in a little bit more chicken.

And so, there's, you know, there's different ways that you can fit that. But we have had some people that are ethical vegans, with PKD really want to engage in a protocol, and we've been able to get some good results a little bit harder. But you know, there's a balance to it to make sure it doesn't overtake your life.

My dietician told me to ask you about the cocoa because we are blind using Google and I'm only getting impatient. So, just have her reach out to me. I don't say it's a pretty individualized conversation. Okay. I'm going to just type things that we just have two minutes. I'm so sorry. I could not get to every single one of your questions. If you want to reach

out to me you have more questions, you can reach out to our support desk, and they forward to me questions. If it's not an individualized nutrition question. I'd be happy to answer it quickly. I'm not the fastest in responding to emails, sometimes I'll pitch over to someone on my team, but I will do absolutely my best. Otherwise, of course, we'd recommend you book an appointment.

And we're really well connected in the dietitian space we're happy to connect you to someone in your area who we know has, wants to look at PKD a little bit differently but would love PKD does our website we do have a keto and low oxalate specific on our blog, you can search through it and find some of those recipes that are plant focused. So that can be a good resource for you and then renew. We've been involved with that program. It is a separate organization, but we're really lucky to be involved. And then of course, you can follow us on social media.

Okay, thank you everyone for letting me be here today. I'm going to go ahead and stop my share. Again, I apologize that we couldn't get to all your questions, but I know you have tons of amazing sessions to be able to get to. And thank you again and for those of you who are learning and moving forward with trying new things. That is you being a pioneer for PKD because your doctors and other medical professionals are seeing how that's impacted us that they can take it back to their patients.

And all of us are involved patients and professionals. It's a collaborative effort to come to solutions and you know, it's a really exciting time to be able to tackle this. I feel like there are options now. So, thank you again for everyone for letting me join you here today and I hope it was valuable.

Krystn Kuckelman: Thank you!

Jessianna Seville: Thank you Krystn for letting me be here today.

Nutrition in Adults

Krystn Kuckelman: That was so wonderful! Wow. That was terrific. And excuse my little blunder there but I think it all worked out.

Jessianna Seville: Hey, that's okay. That was a little warm up before the race, right?

Krystn Kuckelman: I got a too excited. And thank you so much and I'm going to stop the recording. Thank you.

Jessianna Seville: You won't need anything else from me. Bye-bye!

Krystn Kuckelman: Thank you!

[Audio Ends]