

Nutrition for Children

Nicole: Our presentation today is nutrition in the PKD Pediatric Population. Here's our activity disclaimer for the PKD foundation. Here's our disclosure, I personally do not have any financial disclosure to share with you. Just a little bit about me, I'm a registered dietician, I'm a board certified as a specialist in renal nutrition. I went to school at Boston University, graduated back in 2000. I've worked at Boston Children's Hospital for about 19 years now. I currently follow the pediatric population of kids with chronic kidney disease, on dialysis, peritoneal dialysis, hemodialysis, and through their transplant process.

I thoroughly enjoy working with children. I've been doing this for many years, it brings me great joy to see kids reach their nutrition and growth goals. When I'm not at work, I enjoy doing all the things outdoors with my family and dogs. And that's a disclaimer that I do have two dogs that hopefully behave through this process. No guarantees. So, our objectives today we're a pretty small group. So, I'm going to keep this pretty casual, feel free to interrupt ask any questions throughout this presentation. Or we can save it for the end, whatever works best. But first, we're going to talk about the general dietary recommendations for PKD. Identify any challenges children with PKD may have to achieve adequate nutrition and growth and identify methods to optimize growth and nutrition and then review nutritional supplements for the pediatric population.

So, is there a recommended diet for PKD? There isn't a specific diet for polycystic kidney disease. They're just general recommendations, that then become more individualized based on a patient's kidney function. So according to the National Institute of Diabetes and Digestive and Kidney Diseases, the general recommendations to follow include, first of all, seek consultation from a registered dietitian for individualized guidance because it is very individualized based on the disease states, electrolytes, urine output, every child is different. So, typically we start off with limiting sodium in one's diet. We talk about maintaining adequate hydration, again, that's very individual moderate amounts of high-quality protein are encouraged. And then as disease progresses, potentially restricting potassium and phosphorus

Nutrition for Children

in the diet and then if started on dialysis protein needs increase due to increased losses through the dialysis process.

So why is a modified diet with PKD indicated. So PKD can lead to a progressive decline in the kidney's function, where the fluid-filled cysts that form on the kidney can make the kidneys larger and cause them to not work as well. PKD can be painful, causing a decrease in appetite. So, if any of our pediatric patients have pain or discomfort, nausea, vomiting, any of that, really the first thing to go is the appetite and then it's really difficult to get in good nutrition with these kids. Once the kidney function begins to decline, the kidneys are unable to filter certain nutrients and they begin to build up in the blood. So, following a renal diet, which is typically low in sodium, potassium and phosphorus may be indicated at different stages in time for patients affected with PKD. It is very variable.

So, when we talk about the renal diet and we put the renal diet in quotes for myself and I work with another dietician with this particular population at Boston Children's. We say that very loosely because we do have specific education materials that we review with our patients, but it is very individual, and no education session really looks the same with any one family or patient. So that's why we loosely say a renal diet. But we do start off with sodium. It's usually the easiest to tackle. Sodium there does need to be adequate intake in order to maintain neurological development and growth for the younger children. But later on, it may need to be restricted to control blood pressure and maintain *[unclear]* [00:44:53] fluid status and then sometimes may need to be supplemented in certain disorders due to sodium wasting.

When talking about limiting sodium intake, we talk about where it's found in our diets. So, 10% of our sodium intake is naturally occurring in just the food that we eat. And then five to 10% is added while cooking or at the table just generally salting our food. But a majority of the sodium intake 75% is added by manufacturers during the processing of foods. Sodium can enhance flavor. It controls the growth of bacteria, and it acts as a preservative. So, when we talk about reducing sodium intake in a patient's diet, we encourage choosing fresh or frozen vegetables without sauces. Some of the added cream sauces

Nutrition for Children

or cheese sauces can be very high in sodium. And then canned vegetables can sometimes be pretty high in sodium as well. We review how to read a food label and we encourage choosing foods that are low in sodium. And by low, we mean less than 140 milligrams per serving.

We suggest decreasing salt added to foods at the table. And we actually suggest not even having a saltshaker on the table just so that they're not inclined to use it. Watch for ingredients in salt substitute, some families may opt to choose a salt substitute because they're missing salt so much. But many times, salt substitutes may use potassium as a substitute. And if on a potassium restricted diet, that's not a great substitute. So instead, we encourage using fresh herbs and spices to flavor foods. Tastes better anyway. We encourage limiting fast food intake as fast food can be very high in sodium. And then the food quality isn't great for our pediatric population or any population really.

So, for protein in the renal diet, we don't say necessarily limiting protein as in restricting protein. We just encourage providing protein to that DRI. And so, for some people that may be just decreasing the amount in their diet to slow down the advancement of PKD. And by DRI sorry, I meant dietary reference intake for those who may not know what that means. So, it's not a restriction, we just will go through what they are eating and maybe paring it down a little bit if there's excessive intake. Although some children who are on dialysis therapy have increased requirements of protein because protein is lost in the dialysis process. And then supplementation may be required for those who cannot meet their needs from foods or fluid alone.

So, here's the recommended dietary protein intake chart for children with chronic kidney disease stages 3 to 5 and 5D and you can see as it progresses in stages and then on to hemodialysis and peritoneal dialysis, the protein intake increases in comparison to the GRI because of the losses during dialysis. And then when we talk about protein, we break it down into animal protein sources and plant protein sources. I think when people think about protein, they immediately think about the animal sources. Where chicken, fish, meat one serving is two to three ounces or three ounces is typically about

Nutrition for Children

the size of the palm of your hands. An egg is a serving size of dairy, a half a cup of milk, yogurt, or one ounce of cheese.

But then protein is also found in our plant-based foods, which is beans where one serving equals half a cup, nuts one serving equals a quarter cup, and then some grains, some whole grains and then some of the ancient, cooked grains also are good sources of protein and quality sources as these foods provide other nutrients, which is important.

So, when we talk about fluid, it's very variable per individual. It really depends on the primary kidney disease, what the residual kidney function is. How the urine output varies. The ability to concentrate urine is important and then the presence or absence of hypertension really comes into play when thinking about total fluid intake for the day. So, we suggest consulting your child's physician. We don't necessarily make that recommendation of how much fluid to drink a day. We really rely on the physician's input. But if perchance your child or yourself needs to be on a fluid restriction, we do have some general guidelines we talk about when we meet with our patients.

We suggest paying attention to foods that are liquid or semi-liquid at room temperature that may not be considered fluid to some people but actually count towards a fluid restriction. So, things like an ice cream that melts to be a liquid at room temperature or jello those really count towards your fluid intake. Or if eating a soup, that broth counts as well. We encourage drinking only when thirsty, which is tricky, of course, I think a lot of people drink when they're in social situations or they're bored. It's the thing that they may differ to and especially when they're restricted, it's really a challenge. We encourage taking small amounts of fluid throughout the day using a small copper glass. For our pediatric patients, we will provide little, small fun dixie cups to use for their fluid intake.

Eating cold fruit is a good way to kind of satiate your thirst. A lot of our patients enjoy frozen grapes, it can really be a nice way to alleviate that thirst. Chewing gum too can increase your saliva and then maybe take away some of that thirst feeling. Gargling with mouthwash or using a breath spray that

may distract or decrease the thirst sensation. And then avoiding high sodium spicy and very sweet foods can make you really feel thirsty.

I was meeting with a patient last week he's a high schooler student. And we were talking about his fluid restriction. And he said the last week of school has been the easiest as far as following his fluid restriction and just because he was so busy with school activities and getting things done that he was distracted and really didn't struggle with his fluid restriction so much. And so, we talked about that kind of moving forward. He notices that he is bored or just sitting down, you know with nothing to do and thinking about having a drink, but he is really close to what his fluid restriction is to go do something to kind of walk away from the situation to see if he can create some kind of activity that will distract him knowing that that's worked for him in the past.

So, moving on to potassium, renal potassium excretion is usually maintained until your GFR or your glomerular filtration rate decreases to less than 15 ml/min². Potassium is frequently restricted to prevent cardiac arrhythmias. Because if the potassium builds up too high in the blood, it can be really dangerous in causing arrhythmia. Children on peritoneal dialysis or if they're on frequent hemodialysis sessions, we have a couple of patients who need to be on dialysis more than three times a week for a variety of reasons. They may not need to restrict their potassium as much or may even develop hypokalemia depending on the diet and the foods that they eat as well. A majority of the potassium is found in fruits and vegetables, although it can be hidden in some other foods.

Here's just a nice chart showing some examples of where some common foods fall in the range of potassium. So, right now is berry season. So, we're really encouraging our patients to eat the raspberries, strawberries, blueberries they're in season and they're delicious and they are a low potassium food. And then as we go up the line peppers, cucumbers. Cucumbers is a lower potassium vegetable. It's really kid-friendly. So, we encourage those for a vegetable source. Melons get to be high potassium. And then a lot of our patients really struggle with potatoes being a high

Nutrition for Children

potassium food and limiting those. Sometimes we have to be really creative of how to get around that.

So, moving on to phosphorus levels in your blood are usually not elevated in the early stages of progressive, chronic kidney disease. Elevated levels do have consequences for bone health and growth as well as long term implications for cardiovascular disease. And bone mineralization may be impaired as early as stage two CKD with abnormal bone turnover by stage three. So, we really try to control our phosphorus levels as soon as we see those start to creep up so that we can prevent that from happening. When we're educating our patients or families on phosphorus and maybe have to limit in the diet, we really break down foods into inorganic sources of phosphorus and organic sources of phosphorus.

Our inorganic sources are hidden or added phosphorus. And they're found in our processed, convenience and fast foods, as well as canned and bottled drinks such as iced tea or iced coffee and then our dark sodas that some of our older kids may like to drink. Phosphorus is used to improve color in foods, flavor or stability. And it's listed in the ingredients section on a food label and can be hidden sometimes so you really have to read through the ingredients. Unfortunately, inorganic phosphorus has a higher intestinal absorption rate of greater than 90%. So, when we talk about reducing phosphorus in your diet these are the foods that we start with. Because as you can tell by this picture here alone, a lot of these foods don't have too much nutrition to offer that would benefit the patient. We really encourage high nutrient quality foods when looking at the diet as well.

So, then there's organic phosphorus, which is naturally occurring phosphorus, and it's found in our protein-rich animal and plant products. Phosphorus is tricky because it's not typically found on the food label. So sometimes you have to dig around to find out where how much phosphorus is in a food. The issue with organic phosphorus is the intestinal absorption is less so it's 40 to 60%, which works in our favor. So, it's not as much as absorbed and they're higher quality, nutrient-dense foods. So, we rarely restrict these foods. These

Nutrition for Children

are the foods that we encourage. And as you can see, a lot of them are high protein foods as well, which is important for our kids who are on dialysis.

When we do or we perform our nutrition education, we typically teach families how to read a food label, it's pretty important to look at what you're feeding your children or feeding yourself. And we focus on quantity. So, for the food label, ingredients are listed in order of predominance with ingredients used in the largest amount being first and then they're followed in descending order. So that's important to note. And if you look at this particular food label, you can see that there are two sources of phosphorus high up on the list. So, we would advise against our patients to choose this particular food item.

So, does your child need a vitamin or do you need a vitamin? So typically, we look thoroughly at the diet first and if able to achieve a well-balanced diet. A vitamin may not be indicated, although as kidney disease progresses and if you or your child has started on dialysis, peritoneal or hemodialysis, we do start a vitamin that has all of our water-soluble vitamins because these vitamins are lost during the dialysis process. So, it's really indicated then, prior to that it's really an individual decision looking at the diet to see if there's any deficits. During chronic kidney disease, we're mindful of some vitamins that can be toxic. So, we really are mindful of decision of starting a patient on a vitamin.

So, when talking about decreasing certain foods in the diet maybe because of high potassium or high phosphorus. We first start with our processed foods and our bottled beverages. If we can get rid of those in the diet and then increase the nutritional quality of the diet in the process. It's just a win-win. So, we'll try to eliminate those processed foods first and then the bottle beverage like iced tea, iced coffee, dark sodas and then as we move down the line if a patient's phosphorus is really high, we won't eliminate dairy products ever. We just suggest maybe scaling back we'll look at how much a particular patient is drinking.

For example, another patient I met with last week she tells me that she has a large cup of milk with breakfast, lunch and dinner and then also take milk

Nutrition for Children

with her meds. So, we started there, and we talked about kind of a more appropriate dose of serving size of milk to have and then we'll see what her phosphorus level does. And then certain fruits, vegetables, whole grains and legumes, these are really the last that we will restrict because they're so nutritious otherwise.

So now we're going to talk about the impact of nutrition and growth in chronic kidney disease. Since poor nutrition is the most important factor contributing to growth failure among infant and young children, it's pretty important to have a dietitian as part of your team. Optimizing calorie intake in your younger children with CKD is the most effective strategy to enhance growth velocity. Growth failure is a major problem for patients with CKD. The greatest risk occurs if CKD starts in your early childhood. It can be complicated by physiological linear height impairment, uremia if that's present and developmental age lagging behind chronological age. So, after infancy growth rate correlates with your GFR where the most significant when the GFR falls below the 25 ml/min as you can see on this chart here.

So, what are some causes of growth impairment for children with CKD it can be any one of these items listed below. Nutritional deficiency not getting enough calories overall, not getting certain micronutrients and vitamins. Ongoing metabolic acidosis can lead to poor growth, uremia build-up in the blood that can make you feel not well, nauseous or appetite, which can then lead to poor nutritional intake, electrolyte abnormalities, anemia, inflammation, and then disturbances in growth hormone metabolism and insulin-like growth factor.

So typically, there can be spontaneous oral intake of less than 80%. And it's not uncommon for this to happen among infants and toddlers with CKD. Especially for patients who are on peritoneal dialysis, there's decreased energy intake, and it's commonly due to just feeling full from PD fluid. I talk to parents about this a lot. And you know, there's only so much real at stake per se with our little patients to have the PD fluid in there and then to have formula for good nutrition or, you know, just eating well, it can be a little bit tricky. And we have to work out around the schedule of the PD in order to

Nutrition for Children

make sure we're getting adequate nutrition. A lot of patients have delay in gastric emptying, which can make them feel full longer and uncomfortable, and then not eat enough, or variation in toxin removal.

So as a dietitian, we perform a full nutrition assessment. And what this looks like is we'll do a complete dietary evaluation, and this includes assessing the patient's appetite. Sometimes we use a dietary collection tool like a food record or a dietary recall, what I think works best for our pediatric population is a typical day's intake. And we'll do a couple of days like what is your intake look like when you're in school? What is your intake look like when you're at home? What is your intake look like when you're visiting your nana or when the babysitter has you? So, we have an idea of a variety of how this child's intake is because it's certainly not the same every single day.

If we're really struggling with finding why a patient's potassium may be high or phosphorus may be high, we may ask the family to use an app to record what the child is eating because that may be the easiest way for them to do that. Just being so with our phones being so prominent and part of our lives just to plug it right into a food record on their phone. We talked about the quality of the diets and potentially improving it if needed, and then we'll review GI symptoms that may be occurring. We will review growth in developmental history. And the frequency of which we see the patients really depends on their age and their stage of CKD.

We'll look at recent and long-term growth, including the following anthropometrics weight, length for less than two years height, if we need to use an alternative way to measure our patients, maybe for those who can't stand, we will do a knee to height measure, a knee height measurement and that helps us to get a better sense of what their height maybe, head circumference, mid-upper arm circumference. Sometimes we'll use body composition tools to see to track percent body fat if indicated. And then, of course, biochemical assessment looking at renal function trends, electrolytes, iron studies, protein markers over time.

We will calculate energy needs and we just use our standard pediatric equations that we use for all of our patients at Children's, for the most part.

Nutrition for Children

Will perform nutrition focus physical exam, looking for malnutrition, we look for edema, skin breakdown any potential nutritional deficiencies by assessing what the patient's hair looks like, is it thin? Is it breaking? Is it falling out? What are their nails look like? Are they strong? Are they breaking? Overall skin integrity? How do their eyes look are they sunk in, are they puffy? We really and sometimes the patients don't even know that we're doing this, we sometimes will do it on the sly, so if they're nervous or what not and we'll make our notes without even telling them if they're upset about it. But a complete assessment includes any kind of indicated education, suggested supplements that may be recommended or additional nutritional lab studies and a plan for additional monitoring if needed.

So, to evaluate for growth and nutritional status, there may be reasons why more frequent monitoring is indicated. If the patient has polyuria and has any kind of electrolyte abnormalities. There is growth delay any comorbidities that influence growth or nutritional intake. If there's a recent acute change and medical status or dietary intake. Sometimes a patient is unable to meet their needs. Preliminarily they may require a feeding tube for short term or long term. Sometimes we need to use an NG tube for just a short period if they're going through an acute illness until they're able to eat and meet their needs 100% by mouth. But sometimes NG tube may be indicated for a longer time period. But not to say that can't be removed later. Because we frequently will put in NG tube and then it gets removed six months, a year, two years down the line. And both have been shown to promote adequate intake to catch up growth over demand feeding for children with CKD.

If our patients are able to eat by mouth, we will encourage some renal friendly what we call calorie enhancers, healthy oils that will suggest adding to pasta, vegetables or heavy cream, maybe putting in a smoothie or some warm cereal same thing with half and half. Unsalted butter to vegetables or toast, mayonnaise, cream cheese and sour cream are other good alternatives. And then we have a variety of nutritional supplements that we use for our patients who really need an extra boost to meet their energy needs. The Suplena is a 53 calorie per ounce nutritional supplement, or 1.8 calorie per ml. And just in comparison, our standard pediatric supplements like Pediasure that you've

Nutrition for Children

probably heard of is one calorie per ml. So, this is definitely more calorically dense. The one carton has 420 calories and almost 11 grams of protein. It's designed for adult patients with CKD, but we can use it frequently for our younger children who are on dialysis and may have higher protein needs.

And then we have Ensure Clear which is 200 ml can and provide 220 calories and seven grams of protein. This is a great supplement for our child who loves juice because it's a juice-based product and it comes in juice box so that is also very pediatric friendly. Then we have Nepro. Nepro is a 54 calorie per ounce formula it is also very calorically dense, along with Suplena, provides 19 grams per protein per serving. Can be very too high for our pediatric population, but maybe appropriate for our older kids or young adults. And then there's a new product out by Kate farms. This is a plant-based product and it's also 1.8 calorie per ml and 20 grams of protein per carton. So, this is good for our patients who can't handle a dairy-based formula. So super exciting to have this new supplement on board.

Here are some other supplements that we frequently use. Renastart is a powder it's suitable for children greater than one year of age. It's low in calcium, protein, chloride, phosphorus, potassium and vitamin A. It's often mixed with other products, as it can't be used as a sole source of nutrition but could be mixed with another toddler formula. And it can concentrate up to two calories per ml, which is very exciting. Then we have Carnation Instant Breakfast where one packet alone is 130 calories and five grams of protein and then the additional calories and protein for whatever milk you choose to add it to. We typically suggest the vanilla and strawberry version as it is lower in phosphorus, but this is a great alternative for families who may not have the means to buy some of these more expensive supplements. And it's easier to find it's right in the grocery store, which is nice that it's so accessible.

And then Renastep is a newer product as well that's also two calories per ml and it's suitable for patients greater than one year, where one carton is 200 ml and 400 calories and eight grams of protein. These are some of the supplements that we use in our dialysis center. Liqua cel is a nice alternative it's one pouch is 30 ml, has 90 calories and 16 grams of protein. It's pretty

Nutrition for Children

sweet, but it's a nice way to get in a good amount of protein and in just a little bit of volume. And then we have Benecalorie where one packet of one and a half ounces or 45 ml, 330 calories and seven grams of protein. And this is a liquid, and it can be mixed into you know maybe some oatmeal or rice cereal. And it's a nice way to get in some extra, some heavy-duty calories. And then Nugo bars, we choose to hand out as a snack within our dialysis center. Each Nugo bar has 170 calories and 11 grams of protein, and our kids really liked them.

So, I thought I'd take a minute to go over a typical day's intake of a patient who's three years old, goes by the initials of LC. So, LC came to us and this is her typical day's intake. So, for breakfast she has Fruit Loops with 2% milk and a banana. Lunch is chicken nuggets and french fries. Dinner is Spaghetti Os with broccoli. Her favorite snacks are Oreos and fruit snacks and her favorite fluids to drink are chocolate milk, orange juice and water. Well, LC's labs came back, and her potassium and her phosphorus were a little elevated. So, they asked us to take a look at her diet and see if we can make some changes.

So just based on this one particular day, I went through and made some changes I try not to kind of rock their world and you know change everything all at once. Because as you can see, there are maybe some concerns for nutritional quality of some of the foods here, but I really want to address the potassium and phosphorus first and then we can dig deep into talking about nutritional quality of specific foods. So, for breakfast, the only thing I would really change is getting rid of the banana. The banana is a very high potassium food and maybe switching that to strawberries if she likes strawberries or even blueberries would be fine. For lunch, chicken nuggets and French fries. Again, those French fries, potatoes are a very high potassium food. So maybe trying some alternative kid-friendly vegetables like cooked carrots or even cucumber slices or something like that. Dinner canned Spaghetti O's we could try making your own version of Spaghetti O's with a fun pasta like a wagon wheel pasta. With some homemade mini meatballs, you can make a big batch and use them through the week. And keep the broccoli it's great source of, it's a great vegetable.

Nutrition for Children

LC's favorite snacks are Oreos so you could keep the Oreos just switch to the golden Oreos or even vanilla wafer cookies I mean fruit snacks are typically fine. Although you know pretty high in sugar. Fluids, switch the chocolate milk to vanilla milk or and then the orange juice to apple juice. When we talk about juice, we really encourage limiting to four to eight ounces at the most in choosing a 100% juice just because of the high sugar content. We just want to make sure it's a 100% juice that they are drinking and then a keto-friendly version of that.

So, I just included a slide with some resources. The PKD Foundation website has a resource link has endless lists of references. I found this cookbook on that website, Cooking Well which looks amazing. The National Institute of Diabetes and Digestive and Kidney Disease they also have a good list of references in regard to nutrition. The Academy of Nutrition Dietetics or professional website is a good resource. The Kidney Dietitian is a wonderful blog online that has some great references and good recipes. On the National Kidney Foundation, I found that they had a list of apps that were really helpful. So maybe check that out if you're into using apps.

Davita kidney care has a fantastic database of kidney-friendly recipes and from what I understand they are they're well tested. And many of our patients have tried these recipes and they come out great and they go back for additional recipes. So, in summary, PKD may require a modified diet. As the kidney function declines intake of sodium, potassium and phosphorus will likely have to be controlled. Nutrition management and pediatrics with PKD and chronic kidney disease is complex. And it really requires the close involvement of a registered dietician as part of your multidisciplinary team. Each patient requires a complete assessment to determine an individual nutrition plan and a follow up plan. Our ultimate goal is to achieve normal growth and with close monitoring of anthropometrics labs and dietary behaviors, this is what we are really aiming to do. So, here's my list of references and then I thought I would see if there's any questions. Okay, thank you.

Nutrition for Children

Dwelyne: Thank you, Nicolle. I appreciate it. This is Dwelyne Williams everyone, your hospitality host. As a reminder, please keep your microphone muted and type any questions you may have into the chat box. We can now begin our Q&A. Any questions if anybody has any out there? Let me see. So, I see no one as shared as of yet. Would give it about I say about one more minute or so just to see if anyone would like to revisit or ask any questions or may kind of like, ponder. You know, Nicolle, you know, I have a question. What do you think is the most, I'm sorry, here we go. We have one question. How early do you recommend using a dietitian, wait until the lab show a need? That is from Ashley, thank you, Ashley, for asking that.

Nicolle: No, I think that's a great dietitian, I think the earlier on the better and you can really start even if the labs are not abnormal, but you can start working on developing healthy dietary behaviors from a very young age. And that's really going to help your child develop good eating behaviors from the beginning. So, I don't think it's ever too early to add a dietitian. And once you see it, you may just need to see a dietitian once and then follow up annually until kidney disease progresses and then it may be more frequently, but you could just see one once and then see what you think.

Dwelyn: That was a great answer. Yeah, I think I agree with you as well. I don't think it's never too early. Ashley, that was a great question. Thank you. Does anyone else out there have any questions? If so, type it into chat, so Nicolle can answer your questions. All right. Well, I would like to thank everyone for joining us at PKDCON - 22. It has been an amazing second day and I'm looking forward to next year everyone. Thank you so much for joining us. And Nicolle, thank you so much. Go Boston Celtics, Go Red Sox. We appreciate you.

Nicole: Next year. Thank you for having me. I really appreciate it.

Dwelyn: We appreciate you as well. Thank you so much.

[Audio Ends]