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# kidney living<sup>®</sup>

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Summer 2017

Issue 19

## TALK TO YOUR **CHILDREN**

ABOUT KIDNEY DISEASE

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XYZ

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XYZ

SUMMER FOODS



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kidney living

A MAGAZINE FOR PEOPLE ON DIALYSIS

IT'S ALL ABOUT MAKING ADJUSTMENTS

After 27 months on dialysis, I was excited to restart my life post-transplant. My goal was to attend graduate school and begin a career ensuring healthy lives for people suffering from disease and illness. The adjustment to life post-dialysis was hard. Similar to when I started dialysis, I had to embrace the emotional, physical, and lifestyle changes that take time to adjust to. I also had to remind myself that kidney disease is lifelong — even now, almost four years after transplant, kidney disease is still my biggest priority.

This issue of Kidney Living emphasizes adjusting to your diagnosis and educating others about kidney disease. Whether you are recently diagnosed or have been living with the disease for years, this issue shares ways to explain your disease to others and remain optimistic about living with kidney disease.

Ewo Harrell

Ewo Harrell, MPH

Patient Advocate, Transplant Recipient,
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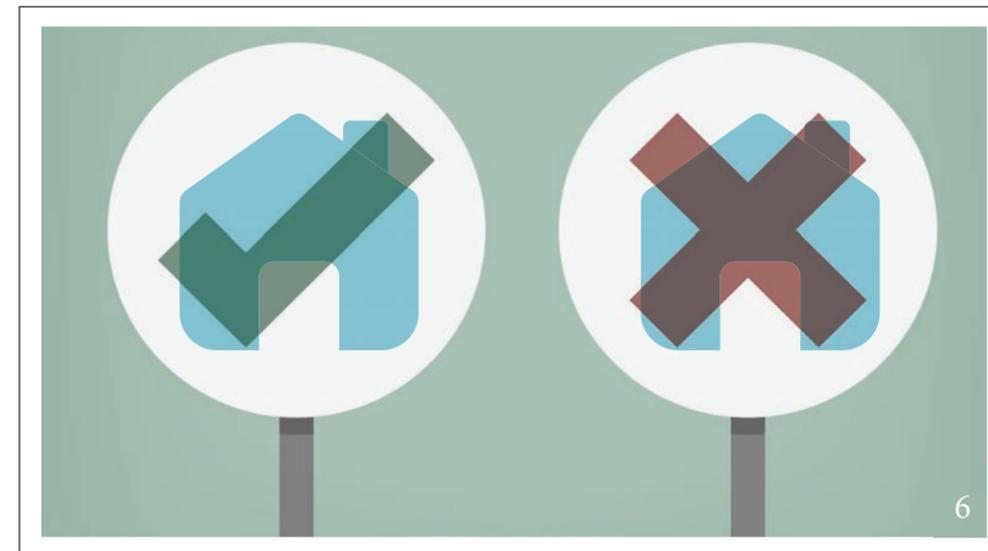


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# Talking to Your Children

About Kidney Disease and Dialysis

xyz

When a family member develops kidney failure, the whole family is affected, even if they don't all show it. Everyone has questions. For children, it may be hard for them to know what to ask or to understand what is happening to their parent.

Here we offer some sample questions and concerns a child might have—and answers to help guide you in talking with them.

Some children are outspoken and ask lots of questions, while others may be quieter and afraid of the answers. Most experts agree that it is important to answer the questions honestly, without reading too much into them or giving more information than is asked for. If your child doesn't express his or her concerns, the questions below may help you begin a discussion about living with kidney failure. Naturally, the words you use are up to you and depend on your child's age and understanding. If you feel you need help either to discuss kidney disease with your child or to help you and your child cope, talk with your social worker.

Some children are outspoken and ask lots of questions, while others may be quieter and afraid of the answers. Most experts agree that it is important to answer the questions honestly, without reading too much into them or giving more information than is asked for. If your child doesn't express his or her concerns, the questions below may help you begin a discussion about living with kidney failure. Naturally, the words you use are up to you and depend on your child's age and understanding. If you feel you need help either to discuss kidney disease with your child or to help you and your child cope, talk with your social worker.

## ASKED KELLI TO CUT...

### 1. WHY DO YOU NOT FEEL WELL SOMETIMES?

Kidneys do a lot of things to keep us healthy. A normal kidney works 24 hours a day, 7 days a week to clean poisons from the blood. Because my kidneys are not working as well as they used to, some of these poisons are building up in my blood. When the kidneys don't work how they're supposed to, it is a little bit like a washing machine that doesn't work right. It may look fine from the outside, but inside there are many important things that do the work. If something doesn't work right, the washing machine doesn't do its job of cleaning the clothes.

### 2. WHY ARE YOU IN A BAD MOOD SOMETIMES?

My being in a bad mood sometimes is not your fault, and does not mean that I don't love you anymore. There are many reasons why I may feel "down" sometimes.

*I am worried about my health.  
I worry about the future.*

*I don't feel good.*

*I don't feel like I used to. I want to do everything that I used to be able to do, but now I can't.*

Things bother me more than they used to. I have lots of worries, and don't feel well enough to think about all of them.

I feel angry, or frustrated, or sad, or scared when I think about being sick.

Often when I snap at you, or seem impatient or angry, I'm not angry at you. I just don't have as much patience as I used to, or as much as I wish I had now.

### 3. WHY DON'T YOU PLAY SPORTS AND RUN AROUND WITH ME LIKE YOU USED TO?

Because I have an illness does not mean that you can't play or make any noise around the house. You can still ask me for things, even though I may seem grouchy sometimes.

Sometimes, I don't feel well enough to play like I used to. Right now, I'm

feeling too tired for active things. I'd like to be able to play like I used to, and maybe when I get used to my treatment and start feeling better, I may be able to do more. But right now, I'm not strong enough. In the meantime, we can try to think of other things we could do together, so that we can keep playing and having fun together. Maybe we can think of some things right now that we can do, like puzzles and games, maybe watching a movie or reading a book.

### 4. WHY DO YOU HAVE TO GO TO THE DOCTOR SO MUCH? I ONLY GO ONCE A YEAR OR WHEN I'M SICK.

The doctor needs to watch how my kidneys are doing. That helps me take good care of myself so I can help to keep my kidneys working. When I go to the doctor's office (or clinic or hospital), many people work together to help me feel the best I can feel. Doctors, nurses, social workers, and dietitians all work together to help me.

### 5. ARE YOU GOING TO DIE?

I may not live as long as I would have, if I didn't have this kidney disease. I'm not going to die tomorrow, or anytime soon, and I hope I will live for a very long time. But everyone dies sometime, so yes, someday I will die. I am making changes in the way I live, to help me stay alive longer.

### 6. WILL THIS LAST FOREVER?

Yes. I will have kidney disease for the rest of my life. But, with the help of the health care team, and you – my family life will go on! Dialysis is a treatment that allows me to keep my blood clean and keep me healthy while I wait for a kidney transplant.

### 7. DO I HAVE KIDNEY DISEASE? CAN THIS HAPPEN TO ME?

Some kidney diseases run in the family. (Note: Your healthcare provider can give you specific information about your disease.) However, you cannot "catch" kidney disease.

## Hemodialysis

### 1. WHY DO YOU HAVE A BAND-AID ON YOUR ARM SOMEDAYS?

To cover up the hole where the needle was during dialysis. This is for the same reason that you put a band-aid on your knee if you scrape it—to keep your skin clean while it's healing.

### 2. DOES DIALYSIS HURT?

Most of the time, no, it doesn't hurt, and I'm able to relax and watch tv, read or take a nap while I get treatment. But sometimes it can be uncomfortable and at times I don't feel good during or even after treatment. To get to my blood to clean it, the staff uses needles which sound scary but I've gotten used to it. It is also really hard to sit still for such a long time.

### 3. WHAT DOES A DIALYSIS MACHINE DO?

It cleans my blood like a washing machine cleans the dirty clothes. If my kidneys worked the way they should, they would clean my blood all the time. Since they don't, I have to dialyze often.

### 4. WILL WE STILL BE ABLE TO GO ON A VACATION?

Yes, we will still be able to take our family vacations. But, it will take a little more planning, and I will have to take time out for my treatment.

## Peritoneal Dialysis:

### 1. WHAT IS THE CATHETER FOR?

The tube lets me put fluid into my belly to do some of the cleaning work that my kidneys used to do.

### 2. WHAT DOES THE FLUID FEEL LIKE?

The fluid makes me feel full, like I just ate a big meal. It doesn't hurt.

### 3. WHY DO YOU HAVE TO WEAR A MASK?

I wear a mask so that germs can't get into my belly.

### 4. WILL THE TREATMENT EVER END?

I will always need some kind of treatment. I might change types of dialysis, or get a kidney transplant.



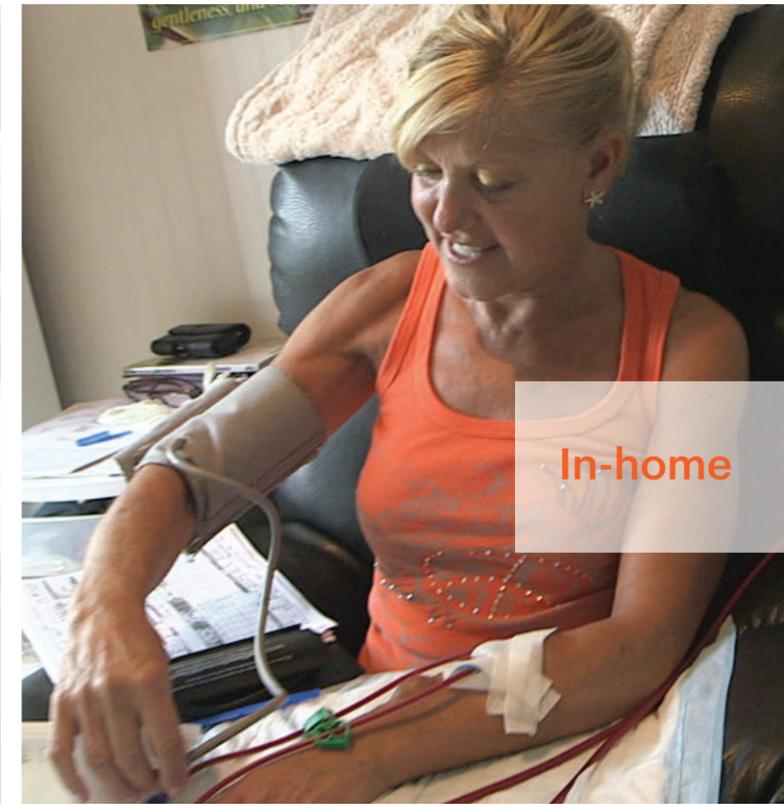
I've been on hemodialysis in-center for a few years now. My healthcare team has been talking to me about home dialysis. Why should I consider dialysis at home?

For many, doing dialysis treatment at home allows more independence and control over their treatment and schedule. You can determine what times work best for you and your care partner and fit the treatment schedule into your life and work schedule.

Doing dialysis at home means you can get more frequent dialysis, which has been shown to decrease the need for medications to control blood pressure and phosphorus. Also, patients report feeling better with longer, more frequent dialysis.



In-center



In-home

**Dialysis is done in the comfort of your own home.**

You do not need to travel to a dialysis center.

**You have more flexibility to choose the time of day to do dialysis.**

You and your dialysis care partner learn how to do treatments independent of the center staff.



**You must have enough space in your home to keep the machine, a water system, (if needed) and supplies**

Your electric and water bills may increase

**You will need a dialysis care partner**

Both you and your dialysis care partner must take time off work or your regular routines to attend training.

Some people may be afraid to have dialysis treatments with blood and needles at home. This is a common concern. Try learning to stick your own needles during your in-center treatments. Have staff teach you and then watch you try yourself until you are comfortable. This will make the transition to home easier once you feel more confident. However, you do not have to stick your own needles to do dialysis at home. Most centers require that you have a care partner trained and present during your treatments. Your care partner will be trained alongside you so you both know how to do everything required during treatment.

It's also a good idea to talk with someone who has done hemodialysis at home – talk to your social worker to ask about support groups in your area or call **NKF Peers 1.855.653.7337** to

get connected with a peer mentor by phone. The fears and concerns you have are normal and others have also faced them. Talk with someone who has overcome them and successfully does hemodialysis at home.

Once you go home, you are not alone! Your healthcare team at the dialysis center will continue to follow you and be available to support you. You will need to see them in the center at least once a month. You will also be given a 24-hour emergency number to call, if needed.

Doing dialysis at home is not for everyone, but it is a great option to consider. The most important thing to remember is you have options! Learn more about them and decide what is right for you and your family.

# learning to *Share My Story*

with kidney disease



**I am** a 46 years old female that has lived with chronic kidney disease (CKD) my entire life. I had a transplant which lasted five years, and have been a hemodialysis patient for the past 13 years. I've always been a very private person, particularly regarding my CKD. I didn't want to be seen as weak, "less than," or different. Therefore, I often downplayed my CKD, sometimes even going so far as to hide it.

However, I have learned that how I see myself, and my disease, makes ALL the difference. Attitude really is everything! Once I gave up fighting CKD and simply accepted it as a challenge, rather than a burden, I began to find peace within me. I realized I was fighting an enormous part of myself and needed to accept myself for who I am. After all, our world is made up of seven billion different people, each with their own beautifully unique characteristics.

When sharing my CKD with others, I often discover most are ignorant of all things kidney-related, which makes sense. If something isn't a part of your life, then, most likely, you are not aware of it. Consequently, my life is the ideal set-up for me to be an educator for awareness. However, first, I had to educate myself by asking lots of questions of doctors, nurses, clinic staff, and other patients; researching everything I could about my disease; knowing my lab results and what they mean; understanding what each of my medications do and how they help me manage my CKD.

Knowledge is power! Once you are well-equipped with the knowledge, you are in the perfect position to be a teacher. Most of my friends, family, coworkers, and even strangers appeared genuinely interested in my story and appreciative of being informed. I truly believe in the power our attitude has on our physical, mental, emotional, and spiritual health.

It has been exceptionally rewarding, inspiring, and empowering to share my experiences with other dialysis and CKD patients. New patients are grateful and feel less overwhelmed and frightened, while long-term patients are responsive to helpful guidance as well as the emotional support of someone who truly understands what they are going through. Remember, we are stronger than we think we are! It is my hope that every person on dialysis understands, and believes that they are the key to their own happiness and well-being.

*Billie Jo Seffrin*



ASKED KELLI TO CUT...  
DESIGN UPDATE

## KIDNEY DISEASE AND

# Family

Most teenagers are preoccupied with concerns about school, parents, friends, and what's happening on Facebook or Instagram. But for 15-year-old Thalya Onelin, dealing with kidney disease is her biggest priority. In 2014, after suffering from nausea, weight loss, and rashes, Thalya was admitted to the hospital and diagnosed with stage 5 kidney disease. Her mother, Chantal, knew something was off, but did not realize the extent of the problem until they went to the hospital.

"As parents, we make it our mission to protect our children, and to know when something is wrong," said Chantal. "When she was experiencing these strange symptoms, we decided to seek out medical assistance right away."

It was then that their world was turned upside down. While they attempted to digest the diagnosis, and understand kidney disease, Thalya's parents knew they needed to remain calm so that they could figure out what to do next. Fortunately, Thalya was much more positive than her parents expected. She was very compliant with her doctors, and always did everything she was told. She was even more concerned about her parent's well-being, constantly asking if they were alright.

The family had to make a few lifestyle changes after Chantal's diagnosis. When Thalya began dialysis, Chantal changed her work schedule from full-time to part-time to attend dialysis treatments with Thalya for three hours, three times a week. The family also had to change their diet. They now had to make sure they were mindful of their sodium intake

and had to limit the consumption of foods that contained potassium and phosphate. They experimented with different spices to enhance the flavor of dishes, and found great substitutions for some of their favorite meals.

"Everyone joined in and celebrated with new recipes. We didn't want to turn the kidney diet into a chore," said Chantal. "We opted to turn this lifestyle change into a discovery of how creative you can be when you're faced with limited options. We were determined to make it a fun experience!"



While Thalya attempted to remain optimistic, her time in the hospital and on dialysis took a toll on her both mentally and physically. Her energy level was very low and she often experienced dizzy spells. On top of that, being on dialysis three times a week was hard on her social life.

"When you're a renal failure patient, your movement is cautious and slow," says Chantal. "You want to be young and vibrant like the other kids, but your body is saying no."

Despite these challenges, Thalya graduated from the 8th grade on time. Determined to not let kidney

disease slow her down, she kept up with her school work and continued to thrive in the classroom. Thalya was fortunate to have a wonderful child life specialist team at Mount Sinai hospital that helped her adapt to dialysis sessions and make them a part of her regular routine. The team arranged for her to receive piano lessons during her treatments every week, which gave her something to look forward to. She made friends in the hospital and was even chosen to join the Youth Advisory Group at Mount Sinai. Thalya's optimism was contagious, and she provided much needed support to other children undergoing treatment at the hospital.

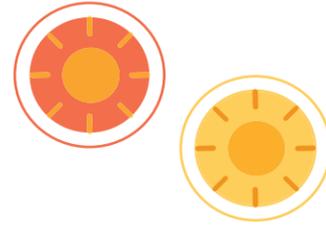
While Thalya is patiently waiting for a new kidney, her mother is determined to raise awareness about kidney disease and the importance of organ donation. For one reason or another, Thalya's family members were not a match, and so they have begun to look elsewhere. Concerned about the long waitlist, Chantal has started a Facebook page to raise awareness and help them in their journey as they seek a living kidney donor. Utilizing the resources from the National Kidney Foundation (NKF) and the new The Big Ask, The Big Give campaign, the family has developed a better understanding about kidney disease and organ donation, giving them the confidence to speak about it to others.

When speaking to her daughter, Chantal says she always reminds Thalya of the importance of perseverance, explaining, "This is a serious challenge but she's going to learn from this. And moving forward, she can tackle anything."

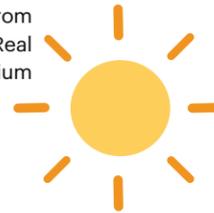
# Summer Starters

Summer means picnics, BBQs, and a lot of gatherings with friends. As well as foods full of potassium, phosphorous, and sodium. So, whether you are grilling at home or packing a **POTLUCK** for the park, use these low-so good and **KIDNEY-FRIENDLY** recipes to add flavor and color to your meals. And keep all the foods you love on your table (or **PARK BLANKET!**).

By Jess Goldman Fong (aka "Sodium Girl"), from her new book *LOW-SO GOOD: A Guide to Real Food, Big Flavor, and Less Sodium*



Spreads and dips are staples of picnic season; hummus being the ultimate portable snack. And creamy cheese landing at a close second. But due to the phosphorous in beans and sodium in cheese, these two items don't often make it into the kidney-friendly picnic basket. But don't fret. Because this cauliflower-based spread not only saves the day, but will quickly become a new favorite for sunny afternoons to come. It is rich, creamy, and definitely healthy. And it goes with anything from crackers, to crudité, to a healthy collard wrap. It's basically the new hummus (don't tell hummus).



## CAULIFLOWER "RICOTTA" SPREAD

Makes 8¼ cup servings

### INGREDIENTS

- 2½ cups roughly chopped cauliflower florets
- ¼ cup unsalted, pine nuts or cashews (soaked for 1 hour)
- ¼ tsp ground nutmeg (optional)
- ¼ tsp dried parsley
- ¼ tsp salt-free garlic powder
- ¼ tsp freshly ground black pepper
- ¼ cup fresh orange juice

### DIRECTIONS

Steam the cauliflower until fork tender, 6 to 8 minutes. Then transfer cauliflower to a high-speed blender and add the remaining ingredients. Pulse until you get a ricotta-like texture. Scrape the sides of the bowl with a spatula to get any missed nuts or cauliflower. Add a little water if mixture feels too thick. Pulse until well combined. Store in an airtight container in the fridge for up to a week.

*Notes:* Add nutritional yeast, other salt-free spice blends (like: BBQ, za'atar, curry!), and other herbs or raw vegetables (like: peeled beets, basil, spinach!) for varied flavors. Then use as a dip, spread, or even filling for a healthy collard green wrap! Basically, anything you would eat with hummus! bath to stop the cooking process.

### ANALYSIS

- Calories: 31
- Carbohydrates: 2.9g
- Total Fat: 2.1g
- Protein: 1.1g
- Sodium: 10mg
- Potassium: 112mg
- Phosphorus: 61 mg



## QUICK FENNEL RELISH

Makes: 1½ Cups (8 Servings)

In summer, food should taste as bright as the weather. Which is why a tangy relish often lands on the table. But even the "sweet," store-bought versions contain around 100mg sodium per 1 tbsp. serving. So, if you want the perk of relish without the sodium and sugar, it's often best to make it yourself. Before you assume this requires too much salt and too much time, though, let me say it's actually very easy. Especially when you give licorice-tinged fennel a quick bath in tangy apple cider vinegar. A mix of mustard seeds, caraway seeds, dried dill, and a little turmeric provide extra bite. And the result is a low-so good impersonator, ready in minutes, begging to top burgers or grilled chicken and fish; zucchini noodles; weekend eggs; or super healthy cauliflower steaks. I, of course, ate mine with a spoon.

### INGREDIENTS

- 1 medium fennel bulb
- ¼ small yellow onion, minced
- 1 cup unseasoned apple cider vinegar
- ¼ cup fresh orange juice
- ¼ cup water
- 1 tsp turmeric
- 1 tsp yellow mustard seeds
- ½ tsp caraway seed
- ½ tsp fennel seeds
- ½ tsp dried dill weed
- ½ tsp red chili flakes
- ½ tsp freshly ground black pepper
- ¼ cup chopped flat leaf parsley (optional)

### ANALYSIS

- Calories: 49, Carbohydrates: 11g, Total Fat: 0g, Protein: 1g Sodium: 17mg, Potassium: 184mg, Phosphorus: 87mg

### DIRECTIONS

Prepare the fennel by washing and cutting off the bottom nub and fronds. Remove outer layer if bruised (and if you care). Otherwise, chop the bulb lengthwise into a few thick chunks. Then use a food processor (or a box grater) to shred the fennel pieces. Place everything except the fresh parsley (fennel through black pepper) in a medium pot. Bring it to a boil and let it cook until the liquid reduces, about 5 to 8 minutes. Let it cool, about 10 to 15 minutes. Transfer to a clean glass container with a lid. Place in the refrigerator until use. Will last up to a week.





**CARROT VEGETABLE NOODLE SALAD WITH SPICY SHRIMP**

*Makes 4 servings*

Give your stove and your pasta noodles a summer vacation with this veggie-filled dish. It's light, healthy, and bursting with spice. Not to mention a tangy avocado dressing to cool it all down (which you'll end up using on everything). This dish can be served cold or at room-temperature, which is perfect for hot summer days and nights. And shrimp can be replaced by any protein that works for you and your diet. Note: it's best to use frozen shrimp to be certain of sodium content, so be sure to look at and read labels to pick products right for your diet.

**INGREDIENTS**

- 5 medium carrots (rainbow if available)
- ¼ – ½ cup Avocado Green Goddess Dressing (see recipe, right)
- 4 oz snow peas, washed and trimmed
- 2 green onions, root ends trimmed, thinly sliced
- 2 red Fresno chile
- ½ jalapeno chile, seeded and thinly sliced (optional)
- ¼ cup chopped fresh basil
- ¼ cup chopped fresh cilantro
- 1 tsp salt-free garlic powder
- 1 tsp salt-free chipotle spice or chili powder
- ¼ tsp freshly ground black pepper
- 12 extra-large, frozen shrimp with tails, thawed, peeled and deveined
- 2 tbsp olive oil for frying
- ¼ cup salt-free chopped peanuts
- 1 lime, cut into 4 wedges

**DIRECTIONS**

Use a vegetable peeler to make carrot ribbons or the grater attachment on a food processor or a box grater to shred the carrots. Transfer to a large mixing bowl and add 1/4 cup of the dressing. Toss to coat well; taste and add more dressing, if desired. Add the snow peas, green onions, Fresno chile, jalapeno, basil, and cilantro. Toss to combine. Set aside.

In a medium mixing bowl, mix the garlic powder, chipotle powder, and pepper until combined. Add the shrimp and toss until coated with the spice rub.

Heat 1 tbsp oil in a large sauté pan or skillet over medium-high heat. Add the shrimp in batches and cook on both sides until nicely seared and the shrimp are pink, about 3 minutes per side. Remove the shrimp to a plate and set aside. Wipe out the pan if it is watery from the shrimp. Repeat with the remaining shrimp until all are cooked, adding more oil, and adjusting heat as needed.

Serve the salad, accompanied by the shrimp, peanuts, and lime wedges in separate bowls and let guests dish up their own plates.

**ANALYSIS**

ANALYSIS  
 Calories 162  
 Carbohydrates: 12.3  
 Total Fat: 11.6g  
 Protein: 4.5g  
 Sodium: 61mg  
 Potassium: 388mg  
 Phosphorus: 158mg



**AVOCADO GREEN GODDESS DRESSING**

*Makes 1½ cups*

**INGREDIENTS**

- 2 garlic cloves
- 1 small shallot, roughly chopped
- ¼ cup tightly packed fresh cilantro leaves
- ¼ cup fresh basil leaves
- ¼ cup chopped fresh chives
- ¼ cup lemon juice
- 2 tbsp lime juice
- 2 tbsp olive oil
- ½ medium avocado
- 2 tsp apple cider vinegar

**DIRECTIONS**

Put the garlic, shallot, cilantro, basil, chives, lemon juice, and lime juice in a blender (or food processor) with 2 tbsp of the olive oil and puree until smooth. Add the avocado and vinegar and blend again until well combined. Add the remaining 1 tbsp olive oil as needed to get your desired dressing consistency.

Store in an airtight container, with a little water on top to prevent browning, in the refrigerator for up to 4 days. Pour off the water before using.

**ANALYSIS**

Calories: 35  
 Carbohydrates: 2g  
 Total Fat: 3.2g  
 Protein: 0.3g  
 Sodium: 2mg  
 Potassium: 61mg  
 Phosphorus: 8mg

**HARISSA HOT SAUCE**

*Makes 1¼ cup Serving Size: 1 tbsp*

Most store-bought hot sauces will contain more than 100mg of sodium per 1 tsp. But you can harness the same heat with the help of dried chilies, fresh chile peppers, and a blender. And by having this sauce on hand, you can quickly spice up any summer dish, from a pasta salad to grilled skirt steak to roasted asparagus. And don't forget about a DIY pizza, burgers, or taco night!



**INGREDIENTS**

- 1 dried ancho pepper (or chipotle, pasilla, guajillo)
- 2 red bell peppers
- 2 tbsp lemon juice
- ¼ cup canola or olive oil
- 1 tsp ground cumin
- ½ tsp salt-free garlic powder
- ½ tsp ground coriander
- 4 tsp fresh lemon juice
- ¼ tsp paprika

**DIRECTIONS**

Put the dried chiles in a small heatproof bowl and pour boiling water over them, just covering them. Let soak for 30 minutes.

Meanwhile, preheat the oven to broil and line a baking pan with aluminum foil.

Cut the bell peppers in half and remove the stems and seeds. Lay the pepper halves in the prepared pan, cut-side down. Broil the peppers until the skin is charred, 15 to 20 minutes. Remove from the oven and, using tongs, put them in a medium bowl. Use the foil pan liner to cover the bowl and let the peppers steam for about 15 minutes. When cool to the touch, use your hands to remove the charred pepper skins and discard. Set the peeled peppers aside.

Drain the rehydrated chiles, and reserve the soaking liquid. Use a knife (and wear gloves) to remove the stems and seeds. Put the chiles and bell peppers in a food processor (or blender), and add the lemon juice, canola oil, cumin, garlic powder, ground coriander, and 2 tbsp of the chile-soaking liquid (or add more if you want it spicier). Blend until smooth; add a little water, as needed, for the desired sauce consistency.

Store in an airtight container in the refrigerator for up to 7 days.

**ANALYSIS**

Calories: 31  
 Carbohydrates: 1g  
 Total Fat: 2.8g  
 Protein: 0.3g  
 Sodium: 1mg  
 Potassium: 51mg  
 Phosphorus: 5mg



For the first time ever, patients with chronic kidney disease were at the forefront of deciding national research priorities. This past April, the National Kidney Foundation's Patient Centered Outcomes Research Stakeholders' Conference brought together 100 patients, caregivers, stakeholders, and academics to identify patient-centered research priorities—and challenges—for kidney disease.

## NKF Patient Centered Outcomes Research Stakeholders' Conference

# KIDNEY RESEARCH: WHAT SHOULD BE DONE?

HOW DO YOU THINK PATIENTS AND CARE PARTNERS CAN BEST INSURE THAT RESEARCH ABOUT KIDNEY DISEASE IS RELEVANT TO THEIR NEEDS?

Many patients have never been involved in research. Even those that are interested often don't know where to start. The goal of the conference was to identify barriers to patient's involvement in research and start brainstorming how to address and overcome those barriers.

"Over the last five years, research with patients and caregivers as active members of the research team has become increasingly important," said Teri Browne, PhD, associate professor at University of South Carolina College of Social Work. "But unfortunately, there's been limited growth of such methodology in kidney disease research and very few studies that actively engage patients

in the development and execution of kidney disease research," added Dr. Browne, who will serve as project lead for the Stakeholders' Conference.

The Stakeholders' Conference was facilitated by both a patient and researcher and featured patients, caregivers, and researchers on a panel discussion and break-out groups. Attendees gained insight into the experiences of patients, caregivers, and researchers, learned more about the importance of patient centered outcomes research (PCOR), and identified best practice strategies for actively engaging patients in kidney disease research.

As part of NKF's commitment to the Stakeholders' Conference,

the Foundation will provide a minimum of \$40,000 towards funding a 2018 Kidney Disease Patient Centered Research Grant. The grant will focus on the top kidney disease priorities identified by patients at the Conference. The Stakeholders Conference is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI

Engagement Award. [kidney.org/pcori](http://kidney.org/pcori)

In addition, NKF hopes that many projects, resources, and research opportunities grow from this conference and that discussion will continue among all stakeholders. We asked our readers to give their feedback too! See the following page for responses. Join the conversation online at [kidney.org/kidneyliving](http://kidney.org/kidneyliving)

**The Patient-Centered Outcomes Research Institute** is an independent, non-profit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions. PCORI is committed to continuously seeking input from a broad range of stakeholders to guide its work. For more information visit [www.pcori.org](http://www.pcori.org)

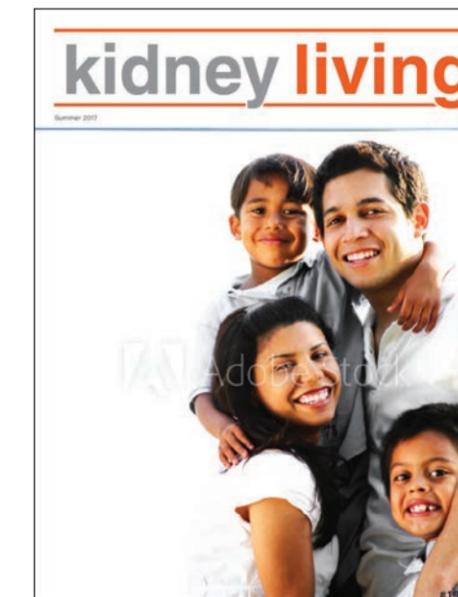
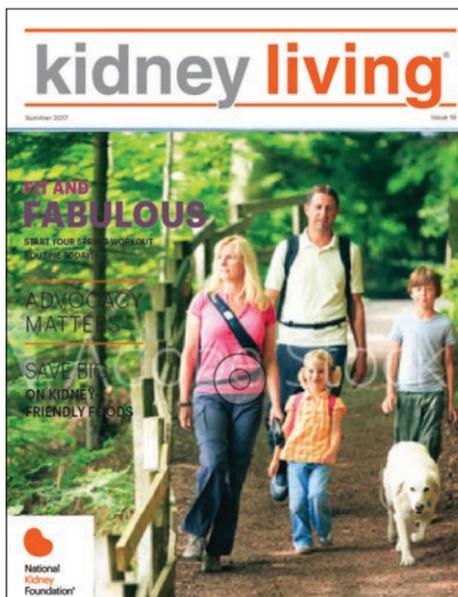
What's PCORI?



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