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AKF in ACTION

Fighting kidney disease and helping people live healthier lives.

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Hope for people with pruritus (itchy skin)

Prunitus is a condition that involves distressing, itchy skin or a "prickly feeling." It frequently affects people who are on dialysis and the prickly feeling can often be felt below the skin or "in your bones." This feeling can be so perpetual and uncomfortable that it may disrupt your sleep and have a negative impact on your mental health and overall quality of life. Some people may feel a sense of shame or anxiety around having pruritus due to marks on the skin and feel frustrated because it seems their doctor doesn't take the condition seriously or even acknowledge it. But, there is hope for people struggling with pruritus.

People with pruritus often say that the urge to scratch is very strong and can be hard to resist. This nonstop scratching can irritate your skin, causing it to turn red or a different color than your usual skin tone. Scratching can also lead to bleeding and infections. Pruritus frequently appears on the skin on your back, arms, head or belly (abdomen) and this irritation can be significant enough that people may feel anxious about going out in public without covering up their skin.

Doctors do not fully understand what causes pruritus in people on dialysis, but anyone dealing with the condition should tell their health care provider even if they have asked about it before or have tried treatments that haven't worked in the past. Be consistent and describe how pruritus feels physically (i.e. "in my bones") as well as how it is impacting your emotional wellbeing and quality of life.

There are many different treatments doctors can recommend. If you are on hemodialysis, you may be able to take a newly approved medication that is added to your dialysis treatment. Ask your doctor if you are interested.

In addition, other treatments your doctor may consider include:

- Increasing the amount of dialysis you get
- Making changes at home to help your skin and relieve the urge to scratch, such as using a special type of lotion every day
- Testing the levels of calcium, phosphorus, magnesium, aluminum and parathyroid hormones in your blood and if any levels are high, making some adjustments to what you eat and drink
- Taking an antihistamine

You can also take certain steps in your home to help alleviate or prevent pruritus, including:

- Switching to soaps and laundry detergents made for sensitive skin
- Using lotion or emollients to moisturize and soften your skin
- Taking baths or showers in cool or warm water, not hot water
- Using a humidifier to add moisture to the air in your home

To learn more about pruritus and how to manage the condition, visit [KidneyFund.org/pruritus](https://www.kidneyfund.org/pruritus) and watch a recorded webinar. You can also use this QR code:

Use this QR code to learn more about pruritus



SCAN HERE



— ‘A wonderful experience I will never forget’: AKF Ambassador Shante Byrd’s inside look at AKF’s 2023 Kidney Action Summit

On May 15, 2023, the day had arrived for my flight to Washington, D.C. I was selected as a patient Ambassador for the American Kidney Fund (AKF)’s 2023 Kidney Action Summit on Capitol Hill and I was very excited and ready for a mini vacation from Georgia, where I live. My mentor and good friend Tamara Walker—also an AKF Ambassador—encouraged me to apply for this year’s summit, and while she wasn’t able to attend herself, I had good company during this day of action.

The next day, I was ready for our day of training, preparation and learning about the workings of Capitol Hill

and AKF. The Ambassadors were given time to practice telling our stories to our senators and representatives about how kidney disease has affected our lives. Although I am used to storytelling because I advocate, educate and volunteer with Life Link of Georgia, I needed a little more practice to make sure my story would resonate with the legislation we were working to garner support for, the Living Donor Protection Act. I was also introduced to my two AKF staff guides, Joy and Lauren, who would accompany me to my meetings on Capitol Hill and to Georgia state Sen. John Albers, an AKF Ambassador and living kidney donor for his son, who would join me for one of my meetings.

In the evening, a reception and dinner tour were scheduled for the Ambassadors. Our bus tour guide was excellent in educating us about all the amazing landmarks and monuments in Washington, D.C., inspiring me to plan a vacation trip back to our nation’s capital to visit some of those landmarks.

On May 17, the Ambassadors headed to Capitol Hill for our day of action. My first meeting was with a legislative aide for Sen. Jon Ossoff. I was nervous, but the aide was very easy to talk to and already familiar with the Living Donor Protection Act. My second meeting was with a legislative aide for Sen. Raphael Warnock. This meeting also went well and I got better at telling my kidney disease story. The third meeting of the day was with a legislative aide for Rep. David Scott. State Sen. Albers was able to join this meeting and he spoke from the perspective of a living donor while I spoke as a kidney disease patient—and Joy and Lauren had our backs! My fourth and final meeting was with the legislative aide for Rep. Rich McCormick. It was interesting to find out Rep. McCormick was previously an emergency room doctor and had likely seen people crash into kidney failure. By 2:30 p.m., my meetings were complete and we headed back to the hotel after an incredible day advocating for the kidney disease community.

Overall, this was a wonderful experience that I will never forget. Truly, it was an experience of a lifetime. I would encourage everyone to apply and take part. Being the face of kidney disease and telling my story is what will pass laws. Thank you, American Kidney Fund, for this opportunity to go to Capitol Hill, represent you and tell my story.

To learn more about becoming an AKF Ambassador and getting involved in AKF’s Advocacy Network, visit <https://bit.ly/AKFAdvocacyNetwork>.

Shante Byrd has lived with kidney disease for 14 years and is an AKF Ambassador.

AKF Kidney Action Summit: in pictures



Receiving AKF grant assistance via debit cards and direct deposit

Ensuring that people with kidney disease can afford their medical expenses has been at the heart of AKF's mission since our founding over 50 years ago. Our need-based programs help people with many expenses related to health care and we are always seeking to enhance and streamline how we provide our grants.

If you are currently receiving your AKF grant payments by check, did you know AKF offers payments by direct deposits, too? ACH direct deposits are a safe, secure way to receive your AKF grant payments. With ACH direct deposits, you receive your grants faster and avoid any potential issues or delays with postal delivery. This payment method is available for some Health Insurance Premium Program grants, as well as AKF's Safety Net and Disaster Relief Program grants.

To receive your grant payment through direct deposit, you must:

1. Have your bank account number and your bank's routing number available
2. Have a valid email address saved in your Grants Management System (GMS) profile

To switch your payments to direct deposit, a grant request must be entered in GMS. Please make sure your bank account and routing numbers are correct when entering this information into your GMS account. An incorrect number will delay processing this information with your bank. Please talk to your social worker or submit your new request.

Ways to Contact AKF

Please do not send messages, voicemails or emails to other departments to request a call back, instead, use the communication methods listed below.



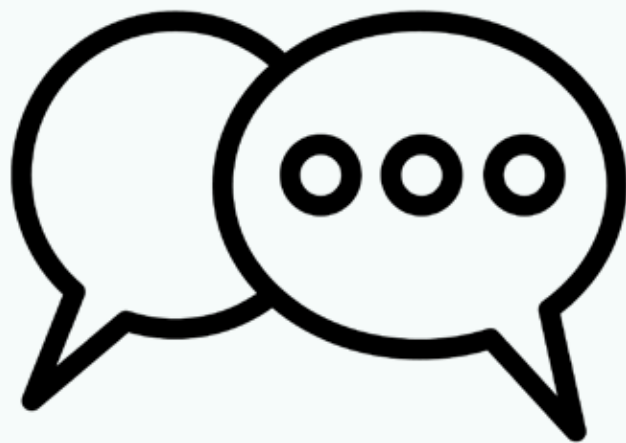
GMS Assist: Visit GMSassist.com to make a phone appointment at a time that is convenient for you.



Through GMS: Message us through your GMS account at gms.KidneyFund.org.



Phone: Call us at **(800) 795-3226** Monday through Thursday 11 a.m. to 2:30 p.m. ET to speak with a live representative.



Introducing AKF's new virtual assistant

To provide more options for patients, caregivers and renal professionals, AKF will be adding a virtual assistant to our Grants Management System (GMS) to better respond to the communication needs of our users. The virtual assistant will be available for solving issues, specifically on the login/registration page of GMS.

What can the virtual assistant do?

GMS Registration Walkthrough

Our virtual assistant can assist you through every step in the registration process, whether you are a renal professional, caregiver, dialysis or transplant patient.

FAQs for Eligibility Criteria

Within our Frequently Asked Questions section of the virtual assistant, you'll be provided an eligibility criteria walkthrough.

FAQs for Application Process

Use our virtual assistant to understand the basics of the application process. This will help get you started once you've logged into GMS.

As the year goes on, we will be expanding what our virtual assistant can do.

Talk with your doctor about treating pruritus (itchy skin)

Pruritus is distressing, itchy skin, which is common in people on dialysis. The itchy feeling can be so constant and uncomfortable that it may disrupt your sleep and affect your quality of life. The good news is there are treatments to help.

Talk with your doctor or dialysis care team about your itchy skin, even if you have asked them in the past. This guide will help you make a plan with your doctor to treat or prevent pruritus.

Get ready for your next doctor visit

- **Be prepared to talk about the pruritus symptoms you have been feeling.**
- **Write down a list of questions to ask your doctor.** Consider the questions on the next page.
- **Bring a pen and paper to write down what your doctor says.** You can also ask a friend or family member to go with you and take notes or ask your doctor to print out the important information for you.

Describe your symptoms in detail



Be open about your symptoms, even if you feel embarrassed—it helps your doctor give you the right care.

Your pruritus symptoms

- How long have you had itchy skin?

 - On what parts of your body have you had itchy skin?

 - Think about the last month. How would you rate your symptoms? Circle one.
- What home remedies or treatments have you used for itchy skin?

 - The treatments I have used:
 Do not help Help some Help a lot

0

1

2

3

4

5

6

7

8

9

10



No itch

Worst imaginable itch



Learn more about pruritus and kidney disease at [KidneyFund.org/Pruritus](https://www.kidneyfund.org/Pruritus)

Ask your questions



During your visit, you may have limited time to ask all of your questions.

Write a number next to each question to rank them from most to least important. Start with 1 for the most important question that you want to ask first, in case you run out of time.

If you cannot print this guide, use a notebook or your phone to track your symptoms, write your questions and take notes.

Questions to ask your doctor

What can I do at home to help prevent pruritus? Are there any products I should use or avoid? Lotions? Soaps? Laundry products?

What foods should I limit or avoid?

What are my blood levels of calcium, magnesium, phosphorus and parathyroid hormone? (High levels of these natural body chemicals may help cause pruritus). If they are not in a normal range, what should I do?

What pruritus treatments can help me?

My other questions:

Check that you understand what your doctor said

Repeat what your doctor said back to them **in your own words**. You can say:

“I want to make sure I understand... (repeat the information). Did I get that right?”





Addressing health disparities in treating chronic kidney disease

On May 9, U.S. News & World Report hosted a webinar sponsored by AKF about battling health disparities in treating chronic kidney disease. Viewers heard from an expert panel, including AKF's President and CEO, LaVarne A. Burton, about some of the most promising efforts underway to improve access to effective kidney care for all. The other speakers were:

- **Lilia Cervantes, M.D., MSCS**, Director of Immigrant Health and Associate Professor in the Department of Medicine at the University of Colorado Anschutz Medical Campus
- **Deidra C. Crews, M.D., ScM, FASN, MACP**, Professor of Medicine in the Division of Nephrology at the Johns Hopkins University School of Medicine and the Deputy Director of the Johns Hopkins Center for Health Equity
- **Elaine Ku, M.D.**, Associate Professor in the Departments of Medicine, Pediatrics, and Epidemiology and Biostatistics at the University of California, San Francisco. Dr. Ku is a member of AKF's Health Equity Coalition and a past AKF Clinical Scientist in Nephrology Fellow.

The webinar was held as part of AKF's ongoing outreach efforts related to our Health Equity Initiative, which focuses on improving prevention and disease management, increasing diversity in clinical trials, increasing awareness and uptake of home dialysis and removing barriers to

transplantation among historically underrepresented groups. Burton discussed the Initiative and AKF's Health Equity Coalition in her remarks, saying: "We've got to bring together different groups and look at how we can work together from our different perspectives to reach those who are most at risk [of developing kidney disease] and provide them with essential tools and education. We also must connect [people with and at risk for kidney disease] with the health care system in a meaningful and informed way so they can be as prepared as possible to deal with the disease."

Dr. Ku, who is an active member of the Health Equity Coalition, also spoke about its importance to the kidney disease community. "The main pillars of the Health Equity Coalition are so important in terms of improving access to home dialysis and kidney transplantation," she said. "Some of the tools that have come out of the coalition were based on the work AKF did in interviews with providers and patients. I think that's so informative, especially the patient perspective, because oftentimes the manner in which patients describe the barriers they face in getting onto the transplant waitlist and what strategies could be helpful to them are not always factors that clinicians think of [when it comes to improving the patient experience and health inequities]."

To watch the full U.S. News & World Report webinar, visit bit.ly/AKFUSNewsWebinar. More information on AKF's Health Equity Initiative, Health Equity Coalition and its efforts to improve health equity in kidney disease can be found at www.KidneyHealthForAll.org.

AKF's Health Equity Initiative is supported by Presenting Sponsors AstraZeneca, Boehringer Ingelheim and Eli Lilly and Company, Travele Therapeutics, Inc., and Vertex Pharmaceuticals; Equity Sponsor Otsuka America Pharmaceutical, Inc.; and Merck.



A 'small inconvenience' saves a life

Watching a loved one battle kidney failure is an excruciatingly painful experience. It's a pain Lynne Wright, a social worker from Pennsylvania, knows all too well. Lynne's husband was born with polycystic kidney disease and she saw the toll the illness took on his body and spirit.

After years of waiting and several rounds of tests, Lynne's husband received a kidney transplant from a living donor in July 2019. "It was extraordinary—a 25-year-old woman who we barely knew and had lost touch with over the years came forward and gave him a kidney," Lynne said. "After that, I just decided that I wanted to make that change for someone else. I felt like I owed the universe something because this wonderful thing had been done for us." Her mind had been made up: she would donate one of her kidneys to someone in need.

"As a social worker, I wanted social justice to play a part in who I chose [to donate my kidney to], so I chose an African-American woman named Roslyn Cooper who was a peer mentor," Lynne said. "I had only met her once

before, but because of my husband's experience [where we didn't know his donor well], I just felt that I had to do it for somebody."

Already in great health when she made her decision, Lynne didn't have to make any major changes to her lifestyle in order to donate to Roslyn—in fact, the biggest hurdle was the testing. "I think my recipient was a little frustrated because the testing takes a while and when you're on dialysis, you want to make it happen," Lynne said.

Lynne's surgery happened on March 9, 2020, just before the country largely shut down due to the COVID-19 pandemic. She said she was more scared of COVID than she was of the surgery itself. "I've had several surgeries and have always done well, including a hysterectomy around five years prior [to the transplant surgery]," Lynne said. "I knew there would be discomfort, as it's still abdominal surgery, but my small amount of discomfort would bring a huge amount of health and longevity to somebody else, just as that 25-year-old woman did for my husband."

Due to COVID-19 forcing workplaces to shut down and switch to telework, Lynne was able to recover at home with her adult children and her husband. "It was a great time to recuperate because my family could wait on me," Lynne said with a laugh. Other than some initial pain and discomfort in her abdomen, Lynne said her recovery process was very smooth and quick. In fact, she felt back to her normal self within two and half to three weeks.

Now, just over three years after donating her kidney, Lynne said she's feeling great. "I get blood work done annually and my remaining kidney is doing fine," she said.

When asked what advice she would give to people who are considering becoming living donors, she said, "It's just a small inconvenience for you that results in an extraordinary amount of longevity and health for somebody else. The payout is so great. I smile whenever I think about [donating my kidney] because I know I did the right thing and it's something I feel obligated to brag about because I want other people to do it. You will not regret it."

To learn more about organ donation, visit bit.ly/AKFOrganTissueDonation.



Save the Date

for the 2nd Annual Dialysis at Home virtual event
hosted by AKF and Home Dialyzors United

Thursday, Sept. 14 from 11 a.m. to 5 p.m. ET

Information on registration will be shared on AKF's social media accounts and through email - stay tuned!

Giving patients on Velphoro a *Voice*

Real patients share their experiences with Velphoro



“Ever since we switched my phosphate binder, my phosphorus has been spot on.”

—Robert



“The flexibility was great for me. I could chew it, I could crush it, or I could break it.”

—Antonio

Watch patient videos at VelphoroVoices.com.

Scan code with your smartphone camera.

The paid testimonial provided is representative of that individual's experience, and not all patients may experience these benefits.

Interested in being a part of Velphoro Voices?

If you have experience with Velphoro, your story could help motivate other patients on dialysis. Fill out this form to be considered as the next voice of Velphoro!



Tell us your story at
BeTheNextVelphoroVoice.com

INDICATION

Velphoro[®] (sucroferric oxyhydroxide) is a phosphate binder indicated for the control of serum phosphorus levels in patients with chronic kidney disease on dialysis.

IMPORTANT SAFETY INFORMATION

- Velphoro chewable tablets must be taken with meals. Velphoro should be chewed or crushed. Do not swallow whole. Tell your healthcare provider about all the medicines you take, including prescription and nonprescription medicines, vitamins, and other supplements. Velphoro can interact with other medicines.
- Tell your healthcare provider if you have any of the following: peritonitis (an infection) during peritoneal dialysis, significant gastric or liver disorder, recent major gastrointestinal (GI) surgery, a history of hemochromatosis or other disease that results in

iron build-up in the body. People with these conditions were not included in clinical studies with Velphoro, and your healthcare provider will monitor your iron levels while you are taking Velphoro.

- Velphoro can cause side effects. The most common side effects are discolored feces, diarrhea, and nausea. Tell your healthcare provider if you have any side effect that bothers you or that does not go away. To report negative side effects associated with taking Velphoro, contact Fresenius Medical Care North America (FMCNA) at 1-800-323-5188. You are encouraged to report negative side effects of prescription drugs to the FDA at 1-800-FDA-1088 or visit www.fda.gov/medwatch.

- Before taking Velphoro, tell your doctor if you are pregnant, plan to become pregnant, or breast-feeding.

Velphoro is available by prescription only. For additional Safety Information, please see Full Prescribing Information at Velphoro.com.

Brief Summary:

Please see Full Prescribing Information for additional information

**What is Velphoro and how should it be used?**

Velphoro (sucroferric oxyhydroxide) is a phosphate binder used to control phosphorus levels in adult patients with chronic kidney disease on dialysis.

How should Velphoro be taken?

Velphoro tablets can be chewed and not swallowed whole. Tablets may also be crushed to help with chewing and swallowing.

The recommended starting dose of Velphoro is 3 tablets (1,500 mg) per day, taken as 1 tablet (500 mg) 3 times daily with meals.

Follow all directions on your prescription label. Your physician may adjust your dose, as often as weekly, by 1 tablet per day until you meet your phosphorus goal.

How is Velphoro available?

Velphoro (sucroferric oxyhydroxide) is available as a 500 mg chewable tablet.

Is there any reason that you cannot take Velphoro after being prescribed by your doctor?

No.

Important note

Velphoro has not been studied in patients with peritonitis while on peritoneal dialysis, or those who have stomach or liver disorders, iron diseases, or those who have had abdominal surgeries. Tell your doctor if you have or had any of these.

What are some possible side effects?

The most common adverse drug reactions to Velphoro chewable tablets in hemodialysis patients included discolored feces (12%) and diarrhea (6%).

The following adverse reactions were identified after had been on the market by some patients and were reported voluntarily.

Tooth discoloration

Skin rash

The risk information provided here is not comprehensive. To learn more, talk about Velphoro with your healthcare provider or pharmacist. The FDA approved product labeling can be found at www.velphoro.us/ or 1-800-323-5188.

To report SUSPECTED ADVERSE REACTIONS, contact Fresenius Medical Care North America at 1-800-323-5188 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

What should you discuss with your physician when taking Velphoro?

Some drugs may interact with Velphoro. Tell your health care provider(s) about all medicines you use now and any medicine you start or stop using.

Tell your doctor if:

You are pregnant or nursing

What happens if you take more than prescribed?

There are no reports of overdosage with Velphoro in patients. Low phosphorus levels should be treated by standard clinical practice.

Velphoro has been studied in doses up to 6 tablets per day.

HOW SUPPLIED/STORAGE AND HANDLING

Velphoro is a chewable tablet supplied as brown, circular, bi-planar tablets, embossed with "PA 500" on 1 side. Each tablet of Velphoro contains 500 mg iron as sucroferric oxyhydroxide. Velphoro tablets are packaged as follows:

NDC 49230-645-51 Bottle of 90 chewable tablets

Storage

Keep the bottle tightly closed in order to protect from moisture.

Store at 25°C (77°F) with excursions permitted to 15 to 30°C (59 to 86°F).

Distributed by:

Fresenius Medical Care North America
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Waltham, MA 02451

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AKF staff spotlight



Name: Melanie Paris

Hometown: Cincinnati, Ohio

What do you do at AKF? I am the Senior Director of Strategic Partnerships and Kidney Disease Education. I am responsible for all public and professional education programs, as well as health equity and outreach.

This includes Kidney Health Coach, condition-related educational content on the AKF website, the Clinical Scientist in Nephrology fellowship program, Kidney Kitchen®, Kidney Action Week and our program-related health equity work. I work with our vice president of patient support and education and my team to create programming that reflects the strategic vision of AKF, evaluate effectiveness of our programs and implement new programs and/or improvements on our existing programs by applying best practices in public health programming, strategy and management.

What is your personal connection to kidney disease? I had a close friend pass away from kidney failure when we were in our 20s. He was living with a transplant, but due to a job loss and other financial hardships, he was unable to maintain his new kidney. He kept his problems to himself because he didn't want to be a burden to anyone. Had

I known then all the information about kidney disease, accessing resources and patient rights I have learned since working at AKF, I believe I could have helped him.

Why are you passionate about fighting kidney disease?

One reason I am passionate about fighting kidney disease is because of my friend's losing battle with kidney failure. Another reason is because in many cases, kidney failure can be prevented when people at risk are provided the right tools to understand their risk, have productive communication with their providers and feel confident in their ability to fight for the health care they deserve.

What is the best part of your job? The best part of my job is knowing that what I do on a daily basis has a direct impact on people living with kidney disease and those in the renal community who care for them and that because AKF provides direct financial support, the impact is significant, direct and immediate. I like that I get to be creative in various projects, solutions and programs that I propose and see something that started as a concept be realized into something tangible. In addition, I like that everyone on my team has work styles and strengths that complement one another. I also love being able to contribute to the professional growth of my team and to the footprint of AKF.

What are your favorite hobbies outside of work? I have assorted interests. I like photography, being active outdoors, restoring old furniture and astrology, which I am only so-very-slightly ashamed to admit. I am a huge reader and I have LOTS of books; anything from management, biographies of former U.S. presidents to historical fiction. And astrology.



Lower Carb Chicken and Veggie Salad

Makes: 4 Servings



Prep time: 25 min

Cook time: 0 min

Recipe contributed by Linda Blaylock of CKD Culinary Consulting, Chef, Certified Nutritionist, Kidney Health Coach, and Creator of The How to Eat for CKD Method

Ingredients:

- 2 tablespoons rice vinegar
- 1 tablespoon Dijon mustard
- 2 tablespoons Swerve® granular sweetener
- 1 ½ tablespoons water
- ½ teaspoon dried oregano
- ¼ teaspoon kosher salt
- 1 teaspoon sesame oil
- 5 tablespoons vegan mayonnaise
- ½ cup red onion, chopped
- 3 cups (9 ounces) cabbage, chopped
- 1 cup (1 ½ ounces) Swiss chard, chopped
- 1 cup carrots, chopped
- 1 5-ounce can, no-salt added, in water chicken breast
- 4 tablespoons dry roasted, no-salt peanuts, chopped

Directions:

1. Combine the vinegar, mustard, sweetener, water, oregano, salt, oil and mayonnaise in a sealed jar or container. Set aside.
2. In a bowl, add the onions, cabbage, chard, carrots, drained chicken and peanuts. Toss well.
3. Shake the dressing vigorously until well combined.
4. Pour over top and mix well to combine.
5. Serve 6 ½ ounces per person.



Cooking Tip: Vegan mayonnaise is used to keep the sodium, cholesterol, potassium and protein lower. You may use regular mayonnaise if your restrictions allow.

Nutrition facts

(1 serving = 6 ½ ounces)

Calories = 197
Carbohydrates = 18 g
Sugar = 5 g

Fiber = 4 g
Calcium = 68 mg
Fat = 13 g
Saturated Fat = 2 g
Trans Fat = 0 g
Protein = 11 g

Phosphorus = 131 mg
Cholesterol = 21 mg
Sodium = 330 mg
Potassium = 425 mg

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[KidneyFund.org](https://www.kidneyfund.org)

Help us fight kidney disease.
Text **KIDNEY** to **52886** to join our mobile advocacy network.

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