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AKF Ambassador

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AKF in ACTION

Fighting kidney disease and helping people live healthier lives.

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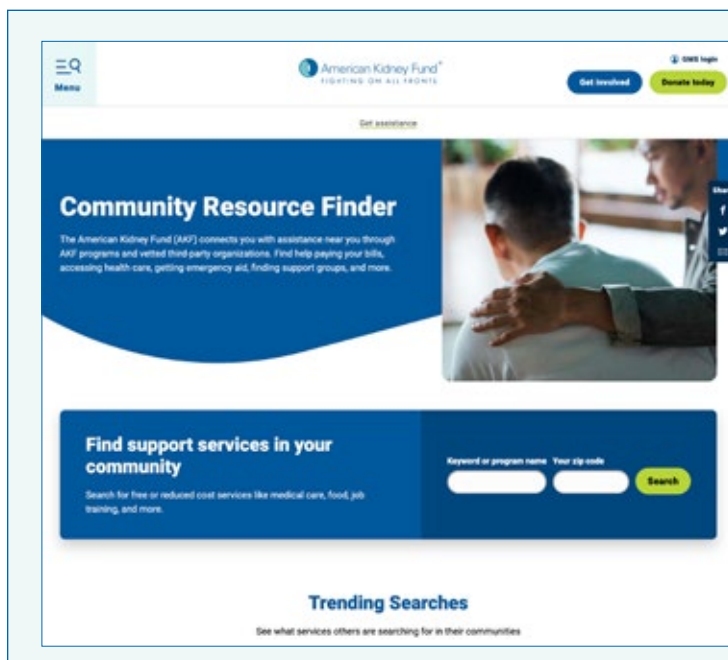
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New AKF tool connects you with resources in your community

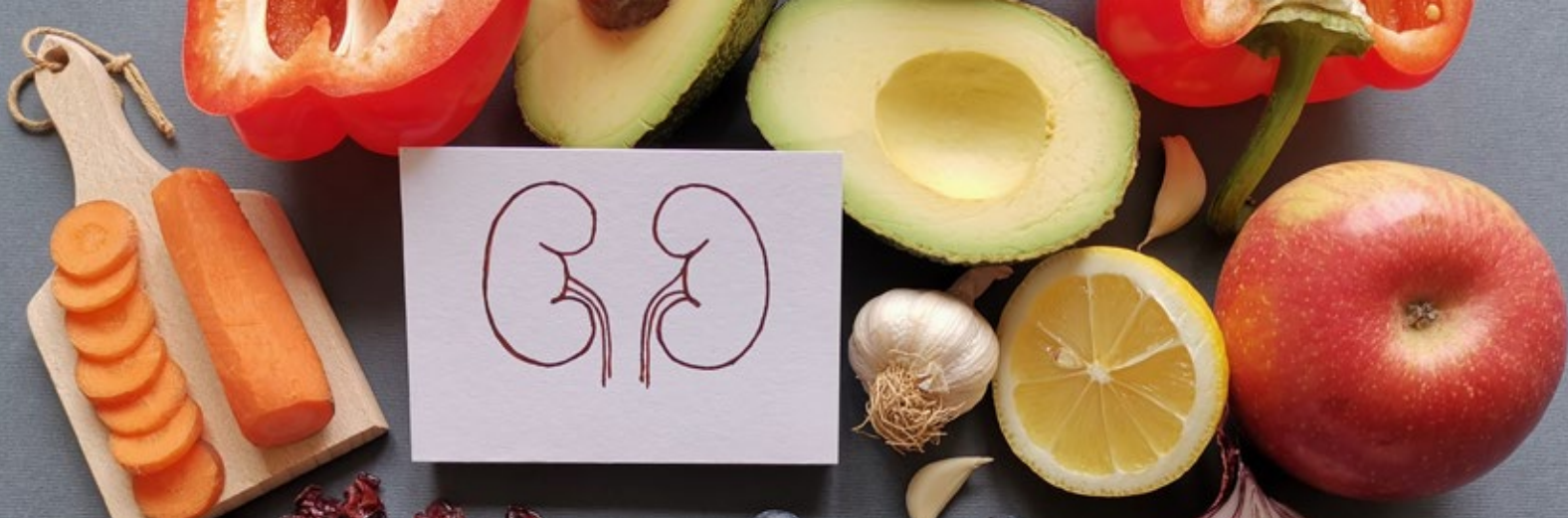
AKF announced over the summer that it has partnered with findhelp, an online social care network, to match people with kidney disease, caregivers and professionals with resources and social services in their local communities. The decision to launch the tool was in response to feedback indicating a substantial need among patients to be connected to resources that will help them as they work to manage their kidney disease. Using AKF's new Community Resource Finder, powered by findhelp, users may enter their zip code so that they can be directed to a comprehensive list of local or regional programs broken into categories such as food, housing, medical care and transit.

The Community Resource Finder is accessible from AKF's website to anyone and within the AKF Grants Management System for registered kidney patients. It will provide links to organizations and resources that can assist with kidney community members' unmet needs. For example, kidney patients who are dealing with food insecurity can use this tool to find food pantries near them, as well as information about government food benefit programs. Patients can also find programs and organizations in their area that can help them pay for transportation to and from dialysis treatments.



To use the Community Resource Finder, visit bit.ly/CommunityResourceFinder or use the QR code below.








— Avoid the superfood trap: tips to feel and do your best

While no specific food or supplement can single-handedly improve kidney function, Kidney Kitchen® contributor, Dr. Blake Shusterman aka “The Cooking Doc®,” explains what dietary choices can help you feel your best.

The ways that kidneys lose their ability to function is complicated, which means it is not realistic to expect individual foods—such as cabbage, cauliflower or red pepper—or supplements (like nettle tea) to reverse the scarring caused by 20 to 30 years of conditions like diabetes and vascular disease (disease of the arteries, veins and lymph vessels or blood disorders). It just cannot happen.

Adopting a kidney-healthy food and fluid plan, rather than relying on individual “superfoods” or supplements, is important for your health when you are on dialysis or have received a transplant. I recommend:

-  **1. Eating more protein:** Once you start dialysis, your protein needs increase. Dialysis removes some of your body’s blood proteins, which means you need to eat more protein to make up for the amount you lose during dialysis.
-  **2. Lowering sodium (or salt):** Minimizing salty foods helps maintain proper fluid balance and blood pressure.
-  **3. Limiting sugary beverages:** High intake of sugary drinks can contribute to diabetes, the number one cause of kidney disease and obesity.



4. Controlling diabetes: Managing diabetes through a balanced food and fluid plan and medicines plays a crucial role in maintaining your health and preventing other chronic diseases like heart disease and stroke.



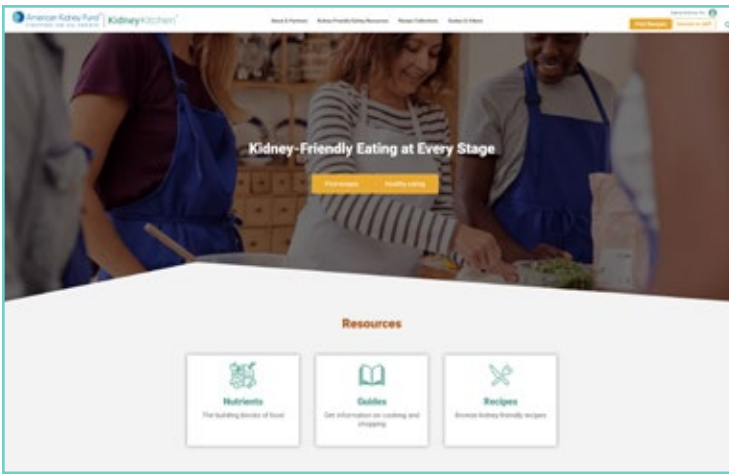
5. Eating more fruits and vegetables: Eating more fruits and vegetables can help you decrease body weight and blood pressure, and maintain your overall health, especially between dialysis treatments. Before loading up on fruits and vegetables, make sure you speak with your dietitian. They can help you understand which ones are safe for your specific potassium requirements.



6. Practicing home cooking: Preparing meals at home allows better control over ingredients, reducing the number of unhealthy additives and extra sodium.

When it comes to kidney health, there is no magical food or quick fix. Rather than wasting your money on an internet product that is unlikely to give you any benefit, focus on adopting a consistent kidney-healthy food and fluid plan that includes more fruits and vegetables, reduced sodium, controlled diabetes and home-cooked meals. Be sure to talk to your doctor or dietitian to see what food and fluid plan would work best for you.

Dr. Blake Shusterman is a contributor to AKF’s Kidney Kitchen®, the author of The Cooking Doc’s Kidney-Friendly Cooking cookbook and the creator of The Cooking Doc®, a popular online cooking show and educational site dedicated to helping people manage their kidney disease through delicious meals.



Kidney Kitchen®: not just for recipes

Did you know that in addition to featuring hundreds of kidney-friendly recipes, AKF's Kidney Kitchen® website also has numerous tips on how to eat healthy when you're on dialysis or living with a kidney transplant? Here are some of those guidelines:

For people on dialysis:



1. Limit fluid intake. Dialysis removes extra fluid from your body, so eating and drinking too much fluid can cause fluid to build up between dialysis treatments. Limiting your fluids will help you feel better and stay healthier.



2. Monitor potassium intake. When you are in kidney failure (on dialysis), it is important to keep a healthy level of potassium in your body. Having too much potassium in the body can be very dangerous.



3. Limit phosphorus. When in kidney failure (on dialysis), you need to limit how much phosphorus you eat. Too much phosphorus can raise your blood pressure, cause calcium deposits in your veins and organs and lead to painful skin sores.

For people living with a kidney transplant:



1. Follow safe food practices. Taking immunosuppressants post-transplant to avoid organ rejection means your immune system is weaker, which results in a higher chance of you getting food poisoning and other foodborne illnesses. It is very important to follow safe food practices to keep from getting sick.



2. Maintain a healthy fluid intake. In general, you should consume about 64 ounces of fluid per day, although your needs may vary, so talk to your transplant center.



3. Limit intake of processed and refined sugar. Eating too much of this kind of sugar can lead to unwanted weight gain and diabetes. Choosing foods with natural sugar, like fruit, is a healthy alternative to sweets, like cookies, cakes and candies.

For more detailed information on healthy eating while on dialysis or living with a kidney transplant, visit bit.ly/KidneyKitchenHealthyEating or use the QR code below.

Use this QR code to learn more on healthy eating while on dialysis or living with a kidney transplant



Want kidney-friendly recipe ideas?

Visit Kitchen.KidneyFund.org

Search through our collection of over 700 recipes organized by meal type, dietary requirements, nutrients, difficulty level and more





Helpful hints for transplant patients receiving HIPP assistance

Once a HIPP recipient receives a transplant, AKF continues assistance until the end of the insurance plan year (usually the calendar year). Although HIPP assistance ends at the end of that year, patients are encouraged to review other programs for which they may be eligible.



Time-Sensitive Information

You are eligible for post-transplant HIPP assistance if you received HIPP assistance while on dialysis for at least three consecutive months immediately before your transplant. You must also continue to meet the program's financial qualifications. You are responsible for notifying AKF by updating your profile within 180 days of receiving your transplant.

Here are the steps to update your GMS account after you have had a transplant:



Claim your account by visiting gms.kidneyfund.org. Use the email address and PIN number given to you by AKF or your renal professional.



Update the "Health Information" section in your profile by adding your transplant date.



Update your facility and contact information in your profile and contact your treatment center for them to verify your facility in GMS. Alternatively,

you can fill out and send a treatment center form to AKF at registration@kidneyfund.org.



Check your existing grant requests/payments in GMS. Make sure the address on each payment is correct. If there are no payments in GMS, you may need to submit a new grant request. To confirm payments, refer to the "How to Confirm a Payment" guide in GMS.



Submit a grant request in GMS. For extended assistance, a current insurance bill no older than 90 days is required for submission. AKF processes grants 10 to 14 business days after the grant is submitted.



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.

Interested in becoming an AKF Ambassador?

Stay tuned and learn more in our virtual Ambassador training on **Wednesday, Oct. 25 from 3 p.m. to 4 p.m. ET**

Visit bit.ly/AKFAmbassadorTraining or use the QR code to the right to sign up for the training



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?”





THE 37 MILE CHALLENGE

Get active and help the 37 million Americans with kidney disease by challenging yourself to walk/run 37 miles this fall.

www.KidneyNation.org/37-mile-challenge-register/

To start your challenge, contact Martin McNutt at mmcnutt@kidneyfund.org or (240) 292-7056.

Congress passes bill to reform the organ transplant system

This summer, Congress passed the Securing the U.S. Organ Procurement and Transplantation Network Act, bipartisan legislation that will strengthen accountability, transparency and the efficiency of the U.S. organ transplant system.

Last year, just 1 in 4 people waiting for a kidney in the United States were able to receive a transplant. Records show that in 2019, the proportion of available deceased-donor kidneys not transplanted was 20%, meaning 1 in 5 of all deceased-donor kidneys were not used.

“Having an effective and efficient Organ Procurement and Transplantation Network is critical to ensuring lifesaving organs are matched with people on the transplant waiting list, including the more than 90,000 who are on the waiting list for a kidney,” said AKF President and CEO LaVarne A. Burton. “It is our hope that through the passage of this bill, the U.S. organ transplant system will be safer, more equitable and more transparent.”





Riding the waves of kidney disease

In the 1980s, AKF Ambassador Ronald 'Ron' Krokey was in the best shape of his life. He was doing triathlons, running 10K races and frequently participating in interoffice competitive events. So, when the same group of businesses decided to hold a health assessment event, Ron didn't hesitate to get evaluated. "Human resources wanted me to take part because I was in such great shape," said Ron.

However, the health assessment revealed that something was off. "They said my blood pressure was a little high, but I didn't think too much of it because I was in amazing shape and relatively young—about 23," said Ron. Still, he decided to have his urine tested as a precaution, which showed protein in his urine. After further tests and a biopsy, it was determined that Ron's elevated blood pressure was caused by focal segmental glomerulosclerosis (FSGS), a rare kidney disease that causes scarring in the filters of the kidneys.

Ron was shocked. Although his late mother had diabetes and was on dialysis at one point in her life, she never had FSGS. However, Ron came to learn that while FSGS is sometimes genetic, it is possible to get the disease even if no one in your family has had it.

Ron was able to avoid dialysis for 11 years by monitoring his blood pressure on a daily basis, eating a healthy diet, taking medication and staying as active as possible.

Unfortunately, that all came to an end in 1999. "I came in for an appointment to do a review of bloodwork and the doctor said that I needed to go to the emergency room and get started on dialysis," said Ron.

From that point until 2008, Ron was on peritoneal dialysis and doing manual exchanges to keep himself alive. "[Peritoneal dialysis] made me feel tired all the time," said Ron. In 2008, he switched to home nocturnal peritoneal dialysis and then to in-center hemodialysis in 2009.

Dialysis is "an intermittent interruption in your day every day of the year," Ron said, comparing the treatment to being in an ocean. "The waves don't stop," he said. "You get hit by a wave and recenter yourself, and then you get hit again. As long as you can accommodate yourself and get used to being in the waves, you're good. You're not on the beach anymore, you're in the water."

"I wanted to help as much as I possibly could and AKF has ample opportunities to do that"

After switching to in-center dialysis, Ron found out about AKF and quickly decided to become an Ambassador to help other people living with kidney disease. "I wanted to help as much as I possibly could and AKF has ample opportunities to do that," said Ron. As an Ambassador, he has taken part in several Kidney Action Days on Capitol Hill in Washington, D.C., and has spoken on behalf of AKF on various occasions. He also has written inspirational letters to kidney patients to help them overcome feelings of powerlessness and depression. In 2018, he received AKF's Hero of Hope award, one of the highest honors given to a kidney patient in the United States, in recognition of his advocacy for kidney patients.

Yet despite all of this, Ron said he wants to increase his involvement with AKF, which decreased after receiving a kidney transplant in 2015. His transplant enabled him to return to the workforce for the first time in several years but returning to work also consumed a lot of his free time.

However, for Ron, being busy is not an excuse to not give back. "[Helping others with kidney disease] is literally part of my DNA," said Ron. "I've been there and have gone through every phase and am well-versed in all the different dialysis options, so it's horrible if—with all of that—I don't help somehow. I have a responsibility [to help] and I take that very seriously."

For more information on FSGS, visit bit.ly/AKFInfoFSGS.

Visit bit.ly/AKFAdvocacyNetwork to learn more about getting involved in AKF's Advocacy Network.

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
920 Winter Street
Waltham, MA 02451

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AKF staff spotlight



Name: Kristle Selby

Hometown: Germantown, MD

What do you do at AKF? I provide primary administrative support in the areas of office management, Administrative Help Desk ticket support and suite-related functions.

What is your personal connection to kidney disease? My partner had kidney disease due to sickle cell anemia and he passed away in 2017. I also have

close friends and family who suffer from some form of kidney disease.

Why are you passionate about fighting kidney disease?

Kidney disease isn't talked about enough. People don't know they have kidney disease until it's too late and that is extremely unfortunate. We hear about other major diseases and don't realize that kidney disease is one of them. Getting the word out about kidney disease is my goal and will continue to be.

What is the best part of your job? The best part of my job is knowing that I am a small part of the mission that helps patients with kidney disease through the work that I do.

What are your favorite hobbies outside of work? I love spending time with my family and being a cheer/football mom.

Kidney Kitchen®



Pumpkin Crepes

Makes: 5 Servings

Serving size: 2 crepes



Prep time: 10 min

Cook time: 30 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



Cooking Tips:

1. Whisk together whipped strawberry cream cheese and cool whip for a perfect and complementary sweet filling. Add fresh strawberries, if desired.
2. Place a sheet of parchment between leftover crepes to avoid sticking and tearing.

Ingredients:

- 1 ½ ounces (42 ½ grams) gluten free flour
- ½ cup pumpkin puree
- 3 large eggs (or vegan substitute such as JUST® egg mix)
- ½ cup heavy cream (or coconut cream)
- 2 tablespoons unsalted butter, melted and cooled (or vegan butter)

Special equipment:

Sifter

Directions:

1. Sift flour in a bowl.
2. Whisk the pumpkin puree, eggs and heavy cream in another bowl.
3. Add the flour and mix until combined.
4. Slowly whisk in the melted butter. Batter should be thin.
5. Heat an 8- to 10-inch nonstick pan over medium low heat until it is hot (water droplets will sizzle when thrown in the pan).
6. Remove pan from the heat, brush lightly with butter and pour ¼ cup of batter and swirl the pan to spread the batter into a circular shape.
7. Put back on the heat and cook about 2 minutes, until lightly browned, top is set and the edges look dry.
8. Using a spatula, gently push one side of the crepe. If it slides in the pan easily, it should be ready and easily flipped.
9. Flip and cook the second side, 20 to 30 seconds.
10. Slide onto a plate (cook time will vary depending on the size of your pan and thickness of your crepes).
11. Do not oil the pan again unless crepes begin to stick. Repeat with remaining batter.
12. Fill with sweet or savory ingredients, roll and serve.

Nutrition facts

(1 serving = 2 crepes)
Calories = 197

Carbohydrates = 9 g
Sugar = 1 g
Fiber = 1 g
Calcium = 57 mg

Fat = 16 g
Saturated Fat = 9 g
Trans Fat = 1 g
Protein = 5 g

Phosphorus = 95 mg
Cholesterol = 151 mg
Sodium = 54 mg
Potassium = 135 mg

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KidneyFund.org

Help us fight kidney disease.
Text **KIDNEY** to **52886** to join our mobile Advocacy Network.

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