



John B., Washington, D.C.
AKF Ambassador

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AKF in Action

Fighting kidney disease and helping people live healthier lives.

3 COVID-19 vaccine frequently asked questions

4 The challenge of living with kidney disease, and how AKF has helped

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50 years of fighting for you

In 1971, a group of friends came together to save the lives of 79 people with kidney failure, and a mission was born. This year, the American Kidney Fund (AKF) is celebrating 50 years of fighting for patients and families. The same spirit of compassion and commitment to people in which we were founded still drives our work today.

Fewer than 55,000 people in the U.S. had kidney failure when AKF was founded. Today, there are more than 785,000 Americans with kidney failure and a staggering 37 million who have kidney disease, making our work more important now than ever.

During our first 50 years, we are proud to have:

- Helped more than 2 million people with financial assistance grants to pay for their insurance premiums and other health care-related costs not covered by insurance
- Funded \$4.7 million in clinical research grants
- Provided award-winning kidney disease educational content to more than 42 million people on our website, **KidneyFund.org**
- Influenced important legislation to benefit those living with kidney disease and living organ donors
- A constant focus on fighting for patients and families

Throughout the next 50 years, AKF will be there, fighting on all fronts, for every American impacted by kidney disease—including you. We are focusing on advancing innovation in treatment and patient-centered research, improving early detection of kidney disease, fighting inequities in health care, expanding access to care, making more transplants possible, and elevating kidney disease so that it is top of mind for the public and policymakers.

Milestones like the one we are celebrating this year are only as strong as the people we work with to build them. During our 50th anniversary, we are celebrating the millions of people we have served over the years. We want to recognize and honor the special moments you've achieved in your life, in the face of kidney disease.

From births and graduations, to taking a special family vacation while on dialysis and getting a kidney transplant, so many of you have experienced meaningful milestones in your lives. To share your story about a milestone you celebrated while fighting kidney disease, visit **KidneyFund.org/milestones**.





MAKE YOUR VOICE HEARD.

*Become an
AKF Ambassador.*

Join the more than 15,000 Ambassadors in AKF's Advocacy Network to raise kidney disease awareness at the federal, state and local levels.

Your advocacy helps us fight for people with kidney disease, caregivers and living organ donors.

One voice can make a difference, but a collective voice is even louder.

Get access to AKF's advocacy training, monthly Ambassador Zoom calls and our private Facebook group for AKF Ambassadors.

Learn more and sign up at
KidneyFund.org/ambassadors

 **American Kidney Fund**[®]
FIGHTING ON ALL FRONTS

5 things you should know about ADPKD

1 What is autosomal dominant polycystic kidney disease (ADPKD)?

Polycystic kidney disease (PKD) is a genetic disease that causes cysts to grow in your kidneys. These cysts make your kidneys much larger than they should be, causing damage to your kidneys. ADPKD is a type of PKD caused by a problem with a specific gene.

2 Can ADPKD be passed down in families?

Yes. Because ADPKD is a genetic disease, it is almost always passed down from a parent who has it. If you have one parent with ADPKD, you have a 50% chance of inheriting ADPKD. If both of your parents have ADPKD, you will be born with ADPKD. It is possible to be born with ADPKD if neither of your parents have it, though this happens in just 10% of cases.

3 What are the symptoms of ADPKD?

Children can sometimes have symptoms of ADPKD, but most people with ADPKD usually do not notice any symptoms until they are between 30–50 years old. Symptoms can include: back and side pain, frequent headaches and blood in your urine (pee).

4 Can ADPKD cause kidney problems?

Yes. ADPKD commonly causes kidney pain and high blood pressure. It can also lead to kidney failure and cause kidney stones. Other complications of ADPKD can include: urinary tract infections, cysts in your liver and pancreas, heart valve and colon problems, brain aneurysms, and preeclampsia (a serious pregnancy-related problem).

5 Should I talk to my family about ADPKD?

If you know you have ADPKD, some of your family members also may have ADPKD. If your family has not been tested for ADPKD, you can encourage them to get tested for the disease. The sooner they learn they have ADPKD, the sooner they can take steps to help keep their kidneys working. There is no cure for ADPKD, but new treatments to manage the symptoms and slow down the progression to kidney failure are available.

For more information about PKD and ADPKD, visit **KidneyFund.org/pkd**. If you or a family member have already been diagnosed with ADPKD, learn more about participating in a clinical trial at **PKDClinicalTrial.org**.



COVID-19 vaccine FAQs

Is the COVID-19 vaccine safe for me if I am on dialysis?

There is no COVID-19 vaccine safety information specific to people on dialysis. However, the vaccine clinical trials included participants who are living with other health conditions, such as diabetes, high blood pressure, heart disease, liver disease, lung disease, asthma and HIV. The results of the clinical trials showed that the vaccine can be safely given to people with these health conditions. Check with your doctor to know if the COVID-19 vaccine is safe for you.

Is the vaccine safe for me if I am living with a kidney transplant?

There was not enough safety information from the COVID-19 vaccine clinical trials specifically for people who take immunosuppressive drugs, such as people with kidney transplants. However, vaccines that do not involve giving a patient a living virus are generally safe. The Pfizer and Moderna vaccines do not involve giving a patient a living virus, so they are expected to be safe to give to transplant recipients unless you have a different health reason not to be vaccinated.

Because not enough transplant patients were included in the trials, we do not know how effective the vaccine may be in transplanted patients. Even if you are vaccinated, it is extremely important to continue to follow all guidelines to avoid being exposed to COVID-19. If you have a transplant, ask your doctor if the COVID-19 vaccine is safe for you.

How does the COVID-19 vaccine work?

The Pfizer and Moderna COVID-19 vaccines are a new kind of vaccine called an mRNA vaccine. The Pfizer and Moderna vaccines are given as a shot, but instead of the shot containing a small amount of the virus like other vaccines, the COVID-19 shot contains a harmless piece of protein from the virus called a “spike protein.” When you get the COVID-19 vaccine, the spike proteins trigger your body’s immune system to make antibodies. Antibodies are what keep you from getting sick if you come into contact with the actual COVID-19 virus. The Pfizer and Moderna COVID-19 vaccines are given in two doses. If you get the first shot of the Pfizer vaccine, you will need to get the second one 21 days later. If you get the first shot of the Moderna vaccine, you will need to get the second one 28 days later. The latest COVID-19 vaccine approved by the FDA is the Johnson & Johnson vaccine. This vaccine only requires one dose and it works like many other traditional vaccines. It uses a harmless virus (called an adenovirus), which is unrelated to the coronavirus, to deliver the same spike protein as the mRNA vaccines.

Did the vaccine clinical trials include people of different races and genders?

Yes. The Pfizer clinical trials had 44,000 people. At first, the Pfizer clinical trials only included adults age 18 and older, but in September 2020 they started including teenagers as young as 16. Half of the participants were male, half were female; 83.1% white, 9.1% Black, 4.3% Asian and less than 3% from other racial groups; 28% of participants were Hispanic/Latino.

The Moderna clinical trial included 30,000 participants age 18 and older across the United States. 52.6% of the participants are male and 47.3% are female. 36.5% of participants are considered to be representing communities of color with 9.7% Black, 4.7% Asian and less than 3% from other racial groups; 20% of participants were Hispanic/Latino.

The Johnson & Johnson clinical trial included 45,000 participants age 18 and older across eight countries. The trial makeup was 59% white, 19% Black, 9% Native American and 3% Asian; 45% of participants were Hispanic/Latino.



For up-to-date information about the COVID-19 vaccine and to read our full list of FAQs, visit [KidneyFund.org/vaccine](https://www.kidneyfund.org/vaccine).

The challenge of living with kidney disease, and how AKF has helped

By Willie Mamie Johnson

I am a 73-year-old Black woman who has worked hard all my life. I grew up in a small town in South Carolina that did not offer many educational or career opportunities for people like me. As a result, I wanted to do all I could to provide unique learning opportunities to those who came from backgrounds like mine. I spent the latter half of my career working as a program administrator at the Oak Ridge National Laboratory in Oak Ridge, Tennessee, where I worked with Historically Black Colleges and Universities and other minority universities by introducing personnel to the laboratory's research capabilities.

My role required extensive travel to universities, recruiting students and faculty for internships, facilitating the award of research and development contracts, developing scientific lecture programs and introducing a seminar on "how to survive" in a corporate, research work environment. I relished the opportunity to help people advance their careers in scientific research, but over time my health deteriorated to the point where I needed help myself.

My first major health challenge came when I had to face and manage my diabetes, while working a very active job at the same time. The second major health challenge I faced was being diagnosed with kidney disease and becoming a dialysis patient. My nephrologist did a kidney biopsy on me and determined that my kidneys failed because of the diabetes, as well as high blood pressure—the two leading causes of kidney disease. The third major health challenge I faced was undergoing **seven** surgeries to obtain an appropriate dialysis access! The fourth major health challenge I faced included amputations of six toes on my feet due to my diabetes and the difficulty in getting my access to pump blood to my toes. The last major health challenge I faced has been most devastating—amputation of two fingers on my right hand. Being an accomplished pianist, my piano playing talent is now severely diminished. Musical pieces I used to play with ease are now a real struggle.



Needless to say, these major health challenges changed my normal way of life. I had to endure multiple therapies, learn how to walk again by using a cane and a walker, and engage in several sessions of hyperbaric-oxygen therapy to help heal my wounds. Despite these challenges, I face each day with grit and determination, and am happy to have an organization like the American Kidney Fund (AKF) fighting for me.

How AKF has been there for me along the way

I am very thankful for all the work AKF has done to assist me and other people like me in meeting the financial obligations associated with living with kidney disease. Living with the multiple physical challenges I face every day takes spiritual will and aggressive determination to survive. My battle is made easier, thanks to the financial assistance AKF provides, because I can focus on my health and not have to worry about how to pay for my care.

Because of AKF's educational materials, recipes, well-organized patient newsletter and financial assistance to offset the costs of my health care, I can live an independent, stress-free and positive life, despite my health challenges. To all those reading this, **keep on fighting the good fight!** You have partners like AKF behind you!

Willie Mamie Johnson is a dialysis patient in Tennessee.

Kidney Kitchen

Crispy, sweet vegetables and soft tofu eggs in a thin, delicate shell make this vegan breakfast a great way to start your day. Check out many more kidney-friendly recipes at [KidneyFund.org/kitchen](https://www.kidneyfund.org/kitchen). As always, please speak with your doctor and dietitian to come up with a food and fluid plan that is healthy for your unique needs.



Vegan Southwest Breakfast Tacos

Makes: 4 medium-sodium, medium-phosphorus, low-potassium, medium-protein servings



Prep time: 30 min

Cook time: 5 min

Total: 35 min

Recipe contributed by Linda Blaylock of CKD Culinary Consulting and AKF's Kidney Health Coach program

Ingredients

- 7 ounces of extra firm tofu
- 1 tablespoon water
- 1 teaspoon lime juice
- 1 ½ tablespoons tahini (sesame butter), may use sunflower or cashew butter
- 1 ¼ teaspoons Mrs. Dash® taco seasoning
- ½ teaspoon black salt, crushed or sea (kosher) salt
- ¼ teaspoon ground turmeric
- ¼ teaspoon ground cumin
- ½ teaspoon ground coriander
- ½ teaspoon dried oregano
- ½ teaspoon dried thyme
- ½ teaspoon dried rosemary
- ½ teaspoon ground mustard
- 2 tablespoons nutritional yeast
- 8 taco shells (La Tiara® recommended)
- 1 tablespoon oil
- 4 tablespoons green or red bell pepper, diced
- 4 tablespoons corn kernels, diced (preferably fresh but can use no salt added canned)
- 4 tablespoons tomatoes, diced
- 8 tablespoons Daiya® vegan cheddar cheese, shredded
- 8 tablespoons fresh cilantro, chopped

Instructions

1. Press the tofu for 10 minutes, draining the water frequently. Once pressed, pat it dry.
2. Place the shells on the lowest oven rack. Do not start the oven yet!
3. Mix the water, lime juice and tahini together.
4. Mix the taco seasoning, salt, turmeric, cumin, coriander, oregano, thyme, rosemary, mustard and nutritional yeast.
5. With your hands, combine the tahini mixture, the seasoning mixture and tofu. Crumble the tofu as you mix it.
6. Now, preheat the oven to warm or 170°F.
7. In a large skillet over medium heat, add the oil. Once hot, add the bell peppers and corn. Cook 2 minutes.
8. Add the tofu mixture and cook 5 minutes, stirring frequently so the tofu does not stick.
9. Stir the tomatoes into the pan and remove from heat.
10. Remove shells when oven reaches temperature.
11. Place 4 tablespoons of tofu eggs into each shell. Top each with 1 tablespoon of cheese.
12. Top each taco with 1 tablespoon of cilantro.

Nutrition facts (1 serving = 2 tacos)

Calories = 309

Carbohydrates = 27 g

Sugar = 1 g

Fiber = 4 g

Calcium = 320 mg

Fat = 18 g

Saturated Fat = 5 g

Protein = 11 g

Phosphorus = 188 mg

Cholesterol = 0 mg

Sodium = 287 mg

Potassium = 252 mg



HERA
CLINICAL TRIAL

Know someone

diagnosed with

Alport syndrome?

If you have Alport syndrome, you may know a family member who also has Alport syndrome, and who would qualify for the HERA Clinical Trial study investigating the safety and effectiveness of an investigational drug in Alport patients.

PEOPLE WHO QUALIFY AND DECIDE TO ENROLL WILL:

- 1 Receive all study-related care at no cost
- 2 Receive close monitoring during the study
- 3 Receive compensation for time and travel expenses (lodging can be foreseen at no cost)
- 4 Have the opportunity to potentially help develop new treatments for patients with Alport syndrome

The study is looking for participants who:

- 1 Are male or female between 18 and 55 years old
- 2 Have a confirmed diagnosis of Alport syndrome
- 3 Have not received a kidney transplant
- 4 Are not currently on dialysis
- 5 Do not have a diagnosis of diabetes mellitus

Study locations:

The Cleveland Clinic Foundation

Jennifer Czerr, 216.444.3256, czerrj@ccf.org

UCLA Medical Center

XiaoXiao Yin, 310.825.7919,
xiaoxiaoyin@mednet.ucla.edu

University of Minnesota Childrens' Hospital

Sarah Lemmage, 612.626.7632,
lemmage@umn.edu

Columbia University Medical Center

Anup Pradhan, 212.305.6842,
arp2209@cumc.columbia.edu

University of Utah

Iran Lavasani, 801.587.3978,
iran.lavasani@hsc.utah.edu

Learn more at alportstudy.com

Real participant reviews of some of AKF's recent webinars:

"This was a great presentation and cooking demo. Thank you! Looks delicious!"

"I can't think of anything else that would've made this webinar better."

"I hope you will do another webinar on this topic soon. I learned so much."

"This webinar was a great resource for me. I enjoyed the warm and thorough presentation and I especially appreciated the Q&A session."



WATCH AND LEARN:

AKF webinars available on demand

AKF hosts free monthly webinars on many important topics relating to kidney disease. We record all of our webinars, so if you can't watch them live, you can always watch them later at your convenience at [KidneyFund.org/webinars](https://www.kidneyfund.org/webinars).

The Cooking Doc®: Potassium Friendly Cooking Demonstration

Are you struggling to control your potassium levels? People with kidney disease may be at risk for hyperkalemia, or high potassium, because your kidneys cannot remove the extra potassium in your blood. Good news—you can manage your potassium levels through the food you eat. **What you'll learn:** potassium considerations when you are cooking, understanding potassium in your foods, substitutions for high-potassium ingredients, and cooking tips and hacks.

Anemia and kidney disease

Do you ever feel tired, cold or weak? Although dialysis can cause some fatigue and weakness, these symptoms may also be due to anemia. Anemia is a complication of kidney disease that happens when there are not enough red blood

cells to carry oxygen through your body, and it affects most dialysis patients. **What you'll learn:** The connection between anemia and kidney disease, symptoms of anemia, benefits and risks of anemia treatments, and new therapies on the horizon.

Advocating for a rare disease

When you have a rare kidney disease, it may seem like you are the only one in the world fighting the battle. But that does not have to be the case. There are advocates all over the country who advocate on behalf of people with kidney disease, and even rare diseases.

What you'll learn: The importance of patient advocacy, what it means to advocate for a rare disease vs. a more common disease, how to become an advocate when you have a rare disease, and advice on overcoming challenges in advocating for a rare disease.



Questions about setting up a new Grants Management System (GMS) patient profile?

Need to reclaim your existing profile? See our step-by-step guide at [KidneyFund.org/gms-registration](https://www.kidneyfund.org/gms-registration).



American Kidney Fund®
FIGHTING ON ALL FRONTS

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WHAT'S INSIDE:

- 50 years of fighting for patients and families
- COVID-19 vaccine FAQs
- How AKF has helped me along the way
- Kidney Kitchen® recipe





VELPHORO

On dialysis,
trying to manage phosphorus?

lighten your day

THE VELPHORO WAY

- Velphoro® (sucroferric oxyhydroxide) is a stronger phosphate binder. Because it's stronger, you can take fewer pills...and lighten up your whole day
- Velphoro is easy to take. Most people were able to maintain phosphorus control with only 3 or 4 tablets per day*—not 3 or 4 per meal as with some other binders

Find out more at www.velphoro.com, and ask your doctor if Velphoro is right for you

*The recommended starting dose of Velphoro is 3 tablets (1,500 mg) per day.

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.

For more information please see accompanying brief summary of full Prescribing Information, or visit www.velphoro.com.



Velphoro is a registered trademark of Vifor Fresenius Medical Care Renal Pharma Ltd.

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PN103781-02 Rev. A 09/2019

 **VELPHORO®**
(sucroferric oxyhydroxide)
chewable tablets

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:

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Patents apply, visit www.fmcna.com/patents

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