



SUMMER 2020 | VOL. 5.3

AKF in *Action*

Fighting kidney disease and helping people live healthier lives.

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PANDEMIC ADVOCACY:

We're fighting for you

People with chronic conditions, like kidney disease and kidney failure, have been hit hard by the COVID-19 pandemic. Though nationwide shutdowns have changed the way we work, the American Kidney Fund (AKF) has not stopped advocating for kidney patients. We have been working with lawmakers and other patient advocacy groups to ensure your needs are considered in any orders and legislation relating to the coronavirus.

In addition to advocating for things like free electronic banking accounts so everyone can easily access their stimulus checks, we also asked the National Governors Association to be cautious in their reopening plans and to not reopen too early. Dialysis and post-transplant patients—especially those part of minority communities—are still at high risk for serious cases of COVID-19. Elected officials should be mindful of the needs of kidney patients when deciding whether it is safe to loosen restrictions.

AKF is part of the U.S. Department of Health and Human Services (HHS) workgroup that includes officials from HHS and organizations in the kidney community. We have suggested ways to address the needs of dialysis and transplant patients during the pandemic. One of our proposals has been for emergency funding for these patients. We started our Coronavirus Emergency Fund in March to help dialysis and recent transplant patients who are struggling financially because of COVID-19. Kidney patients are dealing with increased costs for things like kidney-friendly food deliveries to their homes so they can avoid grocery stores and private transportation to dialysis so they do not have to be around others on public transportation. We asked Congress to include funding for our

emergency fund in the next COVID-19 federal aid package so we can help patients on a longer term, monthly basis.

Through our Coronavirus Emergency Fund, we have so far given one-time grants of \$250 to 10,000 patients—a total of \$2.5 million! If you are struggling to keep up with costs, ask your social worker to apply for an emergency grant for you or you can apply yourself through your Grants Management System (GMS) account at gms.kidneyfund.org. Grant requests are fulfilled as funding becomes available.

The 14,000 AKF Ambassadors in our Advocacy Network have helped us advocate for patients during the crisis by:



Urging Congress to ensure that hospitals and transplant centers have enough protective and treatment equipment to keep patients and staff safe, and prioritize any postponed kidney transplants after the crisis is over.



Requesting that Congress include health insurance protections in the next COVID-19 aid package that would allow people to sign up for health plans outside of normal open enrollment periods and make sure people who lost their jobs during the crisis can keep their insurance.



Asking Congress to ban “surprise bills” in the next COVID-19 federal aid package. Surprise bills can be much higher than your normal copays or coinsurance, and they have led to financial hardship and even ruin for some patients. Anyone with COVID-19 symptoms should be able to receive testing and treatment without having to worry about costs.

For the most up-to-date information and resources for kidney patients during the COVID-19 pandemic, visit KidneyFund.org/coronavirus. To learn more about the work our Advocacy Network does and to sign up to become an AKF Ambassador, visit KidneyFund.org/advocacy.



Patrick and Tina

THE GIFT OF THE STORM:

Surviving COVID-19 as kidney transplant recipient

By Patrick Gee

When I received my kidney transplant in April 2017, I had a new lease on life. Three years and a global pandemic later, my life was on the line because of the immunosuppressive medicines I take to stop my body from rejecting my transplanted kidney.

In mid-March I traveled to Washington, D.C. from my home in southern Virginia for an advocacy event related to World Kidney Day. Before traveling, I contacted my transplant center to make sure it was safe for me to take this day and a half long trip. Back then, there wasn't as much known about COVID-19 and how dangerous it could be for immunocompromised people as there is now, aside from simply knowing that we're in the at-risk category. The transplant center approved my travels and instructed me to take the precautions that are now commonplace—wearing a face

mask and gloves, carrying hand sanitizer with me for when soap and water were not available, and practicing social distancing—which I did.

By the time I was traveling home from D.C., just 36 hours after I originally spoke to my transplant center, things had changed drastically. The center contacted me to let me know they recommended that I self-quarantine for the next four weeks as a precautionary measure due to the rapid increase in positive COVID-19 cases nationwide. The next day, my pastor called to tell me that one of the members of our church tested positive for COVID-19. He knows that I am immunocompromised, so he encouraged me to notify my transplant center and call the COVID-19 hotline for our area. After I told the hotline that I have a kidney transplant, am immunocompromised and have been in the presence of

someone who has COVID-19, they told me unfortunately all they could do was advise me to stay quarantined since I was not showing any symptoms at that point.

My wife, Tina, who coincidentally returned home from a business trip in Tennessee on the same day I returned from D.C., was also feeling great. A couple of days later, however, Tina had a fever, began coughing and had a runny nose. I took her to the emergency room and she was discharged a few hours later with no definitive diagnosis. She was also told to self-quarantine, which she did.

I soon began showing the same symptoms as Tina, except I was also nauseated and had low energy. I contacted my primary care doctor and my nephrologist every day for the next four days to update them about my condition and schedule a test to see if I had COVID-19. I took the test and waited for the results to come in. Tina became progressively worse during this time, so I took her to the emergency room for the second time in the 10 days since we both returned home from our trips.

Hospital security were not letting people accompany patients into the waiting room because of the virus, so I had to drop Tina off in the parking lot. She could barely make it to the emergency room from where security had me drop her off. She had to stop several times to catch her breath and even had to sit down on the curb to rest for a bit because she was that weak. She was admitted to the hospital with pneumonia and eventually found out she was positive for COVID-19. When my test results came back, I found out I also tested positive. My symptoms stayed pretty much the same for the next few days.

Tina was released from the hospital after six days and we made sure to socially distance from each other as much as possible at home while I was

continued on next page >



POST-TRANSPLANT TESTING Program

Are you a recipient of a kidney transplant within the last ten years? Talk to your doctor about the option for a genetic test and if this is right for you. The American Kidney Fund is providing assistance to cover innovative new blood tests that offer ongoing tracking of the health of a transplanted kidney to look for kidney injury or rejection without the need for a kidney biopsy.

ELIGIBILITY REQUIREMENTS:

- Up to 10 years post-transplant
- Annual income up to 400% of Federal Poverty Level (FPL)
- Out-of-pocket costs associated with the blood test

HOW TO APPLY:


- Grants are provided as a direct deposit or check directly to the patient
- One annual grant up to a maximum of \$1,200
- All grant requests must be submitted online at gms.kidneyfund.org by the patient, designated caregiver or renal professional


QUESTIONS?


Contact the Patient Services Department at registration@kidneyfund.org or 1-800-795-3226.


taking care of her. We also wore masks at home and made sure to practice the handwashing techniques suggested by the CDC. As Tina started to get better over the next couple of weeks, I started to get worse; I had low energy, confusion, blurred vision, decreased urine production, body aches, chills, coughs, dizziness and chest tightening. I went to the hospital for tests but luckily never had to be admitted.

As Tina and I continue to recover from the effects of COVID-19 on our bodies, here are a few tips that helped us to survive the worst of this storm:

 **Stay in a state of readiness.** During a telehealth visit with my doctor during quarantine, we discussed my emergency medical readiness plan. In this plan, I keep an updated list of medicines, emergency contact numbers, health summaries, a 3-week supply of non-perishable kidney-friendly foods and a 90-day supply of my immunosuppressant medicine.

 **Practice what you preach.** In February 2018, I changed my nutritional lifestyle so I can be as healthy as possible and keep my transplanted kidney. Being diabetic, I am eating to manage that condition as well. I had lost almost 75 pounds since February 2018, and Tina and I lost an additional combined total of 32 pounds due to the toll COVID-19 took on us. Since I have learned to manage my health better than in the past, my weight loss physician felt it might have contributed to me surviving COVID-19 even though I have two of the major risk factors (diabetes also puts people at high risk).

 **Find your peace amid the storm.** While Tina and I were recovering, we had to figure out where our inner peace had gone. Watching and reading the news and checking social media were beginning to suck our mental wellness dry—nothing was positive, encouraging or motivating. We decided to temporarily separate ourselves from the world and shut everything and everyone out except for our medical care team, church clergy and close, trusted family and friends. Being sick with COVID-19 and trying to maintain my other illnesses was exhausting and burdensome. Having an opportunity to decompress and sit peacefully for my mental health allowed me to focus on my wife and assist her with her recovery, as she did for me.

 **Seeing the “gift of the storm.”** One of the greatest lessons that I have learned about this pandemic is how important our faith is, amidst our affliction, as well as our healing. I listened to the doctors, nurses, researchers, and scientists, but I heard God. In the beginning, middle, and end of the storm, COVID-19 is not bigger than our faith, which only strengthened. Our belief allowed us to endure the storm through our healing, comfort and restoration.

Patrick Gee is an Ambassador in AKF's Advocacy Network, a health care consultant and consumer advocate, and the founder of a nonprofit health and wellness organization.

AKF staff spotlight

Name: Jemetra

Hometown: Sacramento, California

What do you do at AKF?

I'm the associate director of professional education at AKF, so my job directly connects me to people kidney patients see in their everyday lives. I manage AKF's online courses for health care professionals—nephrology nurses, dialysis technicians, renal dietitians and renal social workers—and I work closely with experts who help to develop them. In 2019, more than 5,000 courses were completed by 3,350 professionals—some of whom you may know!

In managing our Clinical Scientist in Nephrology (CSN) Program, I see firsthand how important clinical research is in improving the lives of kidney patients. Our CSN fellows are constantly working to advance knowledge of kidney disease as nephrologists, but they're also teachers, advocates and lifelong students who are lead investigators

at top universities and medical institutions nationwide.

I also love managing our Carolyn Wilson Dialysis Patient Scholarship, which provides kidney failure patients living in Arkansas, Louisiana and Oklahoma with an opportunity to further their education without the burden of tuition fees. If you live in one of these states and want to apply for a scholarship, visit [KidneyFund.org/scholarship](https://www.kidneyfund.org/scholarship) to do so before the July 10 deadline!

Do you have a personal connection to kidney disease?

My grandfather on my father's side was a dialysis patient.

Why are you passionate about fighting kidney disease?

My grandfather was born and raised in rural Mississippi. He had no substantial opportunities to be educated about the importance of living a healthy lifestyle and making healthy food choices. I'm passionate about fighting kidney disease and providing education about the disease to others so they can hopefully avoid dialysis.



Jemetra's team at AKF surprised her with treats for her birthday.

What is the best part of your job?

Having the opportunity to work at an organization committed to educating under-served and disadvantaged communities by providing resources, services and information that is easy to access and understand.

What are your favorite hobbies outside of work?

I love traveling to warm, sunny beaches and cooking. I also enjoy reading when I have the time—I have two young boys at home who keep me busy!



New to dialysis? Learn more about how to adjust during your first 30 days.

- Downloadable checklist of important questions to ask your care team
- Video advice from other dialysis patients
- Patient webinars, kidney-friendly diet information and more

Visit [KidneyFund.org/first30](https://www.kidneyfund.org/first30) to learn more

FIRST30



Amgen is a supporter of the FIRST30 campaign



Kidney Kitchen

This pasta salad is easy to make, and it stays good in the refrigerator for up to four days. Check out many more kidney-friendly recipes at Kitchen.KidneyFund.org. 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.



Ingredients

- 1 pound small pasta noodles (penne, farfalle, elbow, or rotini)
- 1 large cucumber, cut lengthwise and sliced into half moons
- 2 cups arugula, coarsely chopped
- 3 cloves of garlic, minced
- 2 tablespoons extra-virgin olive oil
- 1 tablespoon white wine vinegar
- Black pepper, freshly ground, to taste
- ¼ cup Parmesan cheese, grated

Instructions

1. Fill a large pot halfway with water and bring to a boil. Add the pasta and cook until al dente (still a bit firm). Drain and run the pasta under cold water to stop the cooking.
2. In a large bowl, toss the noodles, cucumber, arugula, and garlic. Drizzle the olive oil and vinegar over the salad, and season with pepper. Stir in the Parmesan cheese and serve.

Summer Pasta Salad with White Wine Vinaigrette

Makes: 8 low-sodium, low-phosphorus, low-potassium, medium-protein servings



Prep time: 10 min
Cook time: 15 min
Total: 25 min

Recipe contributed by
Susan Zogheib, MHS, RD, LDN



Tip: You can use any number of salad greens in this salad. Baby spinach, romaine lettuce, and red- and green-leaf lettuces all swap in nicely.

Nutrition facts

(1 serving)	Fiber = 4 g	Protein = 9 g
Calories = 238	Calcium = 54 mg	Phosphorus = 119 mg
Carbohydrates = 43 g	Fat = 4 g	Cholesterol = 3 mg
Sugar = 2 g	Saturated Fat = 1 g	Sodium = 62 mg
	Trans Fat = 0 g	Potassium = 165 mg



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.

Stay cool: if you get hot and sweaty, it can make you thirsty and want to drink more water.



Managing fluid intake during hot summer months

Managing your fluid intake is especially important during the summer, since hotter temperatures and participating in more outdoor activities can make you thirstier than normal. Having too much fluid build up in your body can make you feel tired and cause headaches and other serious health problems. Learn

more about managing your fluid intake and get some tips on how to cope with thirst in our new video library on Kidney Kitchen™—Kitchen.KidneyFund.org/videos. You will also be able to find videos on sodium management, cooking hacks, recipe videos and more.



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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 **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).

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Patents apply, visit www.fmcna.com/patents

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FIGHTING ON ALL FRONTS

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KidneyFund.org

Find important information and resources for kidney patients during the COVID-19 pandemic at [KidneyFund.org/coronavirus](https://www.kidneyfund.org/coronavirus).

WHAT'S INSIDE:

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- Surviving COVID-19 as a transplant patient
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