



FALL 2020 | VOL. 5.4

AKF in *Action*


Fighting kidney disease and helping people live healthier lives.


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Navigating COVID-19 reopenings as a dialysis patient

By Katie Pickard, LCSW NSW-C

How important is it for you to have a physical connection with others, versus your risk of becoming infected with a potentially serious case of COVID-19? As some states and localities are reopening and loosening their shutdown restrictions, you have to negotiate with yourself for the safest outcome that still gives you some joy and connection to the outside world. There are ways to both be safe and have an enjoyable time.

Can I make plans with friends?

Suppose a friend invites you to dinner for the first time in months now that restaurants in your area are open again. You consider that this would likely be an inside event with other people close by, and you cannot wear your mask when you eat or drink. You decide that this is

a risky activity, but it does not mean you have to say no altogether. An alternative suggestion might be to meet your friend at the park for a picnic. You will still get to see your friend, but this way it will be done in a much safer environment than inside a restaurant.

What if those around me don't follow the rules and aren't wearing a mask?

Instead of focusing on what other people are doing, focus on what you can control in this situation. If you are going on a walk in your neighborhood and see a neighbor not wearing a mask, cross the street to maintain a comfortable social distance from them. You can put your focus on listening to an enjoyable podcast or make a call to a relative, or other things that bring joy to your life. These activities deserve your time, instead of spending your time getting frustrated with people who aren't wearing masks.

What can you do when you are anxious or stressed about COVID-19?

Take the time you spend worrying and replace that time with something you enjoy. Changing your behavior can help you have more positive thoughts and improve your mood. If you notice you are spending a lot of time alone in your home, it might be helpful to create a schedule that focuses on doing things you like and

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COVID-19 reopening checklist

- Make plans to stay safe if you are getting back to your regular routine 
- Ask your dialysis center which of their safety measures will stay in place long-term 
- Find out what resources are available to you during the reopening period 
- Discover new ways to spend time with others and socialize 
- Continue to practice good hygiene to reduce your chances of getting sick 
- Talk to your doctor about additional special steps you or your family may need to make to stay safe and healthy 
- If you feel sick, call your doctor right away and stay home 
- Be prepared now in case of a future health emergency, quarantine or isolation period 

For more COVID-19 resources and information for kidney patients, including a full checklist of important reopening steps to consider, visit KidneyFund.org/coronavirus.

Navigating COVID-19 reopenings, cont.

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connecting with others. Consider scheduling time to: talk on the phone with a relative, fly a kite in the park, go for walk or hike, play an online game with a friend, or send a letter to someone you know who is isolated in a nursing home. Another way to destress is to find a relaxation technique that really works for you and stick with it—download a free app for guided meditation on your phone, do breathing exercises, try aromatherapy, or listen to music.

Still staying home? Use this time to reflect on your treatments.

Having some down time is a great opportunity to reevaluate what may be the best treatment option for you in your current situation. Since you are in control of this decision, you should weigh the positives and negatives of each dialysis modality. Peritoneal dialysis and home hemodialysis give you more independence and they offer you the alternative to dialyze from the safety of your home—something that could be especially beneficial right now or for future health emergencies. In-center hemodialysis is a better fit for you if you prefer a medical professional there to do your treatments and take care of you, or if you enjoy being around other dialysis patients during treatment. If you are not already on the kidney transplant waiting list, you could take this time to find out what you need to do to get on it. You could also spend time asking people in your network to become a living donor for you or starting a social media page dedicated to spreading the word about needing a donor. A kidney transplant is major surgery but you would no longer need dialysis for as long as your transplant lasts. This might be the best choice for you if you want to return to work or increase your quality of life. Choosing medical management—stopping dialysis and going on hospice care—is also a treatment option that is not often discussed, but it is available.

If you are considering changing your treatment modality, discuss your situation with your nephrologist, social worker and other members of your care team. Your care team can provide you with education, connect you to resources, help you problem-solve, advocate for you, and just listen when you need it. You are not alone! Please have the courage to reach out!

Katie Pickard, LCSW NSW-C completed her Master of Science in social work in 2006 from the University of Texas at Arlington. She has devoted herself to nephrology social work since that time and currently serves as a licensed clinical social worker at Satellite Healthcare in Austin, Texas.



FSGS and the APOL1 gene

Focal segmental glomerulosclerosis (FSGS) is a rare kidney disease that causes scarring on your kidneys' filters, which are called glomeruli. This scarring makes it hard for your kidneys to filter out toxins and waste from your body, causes extra protein in your urine, and leads to decreased kidney function and kidney disease. Over time, most people with FSGS will develop kidney failure.

Though the cause of FSGS is unknown in many cases, some causes of FSGS have been identified. One of those causes is a variant, or variation, in the APOL1 gene—a gene that helps to make your body's immune system work. Everyone has two copies of the APOL1 gene, but some people could have two variants of the gene instead of none or one, which increases their risk for FSGS and kidney

disease. The variant in the gene occurs primarily in Black people or people of African, Caribbean or Latin American descent. While kidney disease affects all races and ethnicities almost equally, Black and Latin American people get kidney failure at higher rates—Black people are three times more likely than white people to progress from kidney disease to kidney failure. The variant in the APOL1 gene is genetic, meaning it can get passed down in families, and researchers believe it could be one of the causes for the higher rates of kidney failure among Black and Latin American patients.

If you know that you have FSGS, you can get tested to find out if a variant in the APOL1 gene caused it. There are simple blood and urine tests that you can have done at your doctor's office, as well as genetic tests. You may need additional tests

to rule out any other underlying conditions that may have caused your kidney failure.

If you know your FSGS was caused by the genetic variant in the APOL1 gene, it is important that you talk with your family about getting tested for FSGS and kidney disease. While there is no cure for kidney disease or FSGS, there are medications and treatments that could potentially slow down the progression of kidney disease to kidney failure. Helping your family to become aware of the genetic link between FSGS and the APOL1 gene can lead to earlier detection of kidney disease, leaving more time for treatment before a family member reaches kidney failure.

To learn more about FSGS and other rare kidney diseases, visit our rare disease portal at [KidneyFund.org/rarediseases](https://www.kidneyfund.org/rarediseases).

KIDNEY HEALTH COACH

Are you passionate
about preventing kidney
disease?

Would you like to inspire
others to live a healthy
lifestyle?

Become a Kidney Health Coach with the American Kidney Fund!

FREE online community
health training course

Up-to-date information about
kidney disease and living a
healthy lifestyle

Visit KidneyFund.org/khc
to get started.



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.



AKF staff spotlight

Name:

Raphael

Hometown:

Los Angeles, California

**What do you do at
AKF?**

I am one of the patient
services coordinators
at the American Kidney
Fund (AKF). I spend

most of my work days talking to patients through their Grants Management System (GMS) account—patients who make GMS Assist appointments or who message us in need of help. I help to answer their questions and may have talked to you at some point! I also answer questions that come in from patients' caregivers and renal professionals about applying for AKF's financial assistance programs and help to process grant requests.

One of the things that has kept me especially busy as of late is our Coronavirus Emergency Fund. AKF started this fund in March to help dialysis and recent transplant patients who are struggling financially due to increased costs related to the pandemic. We have processed \$3 million in grants to 12,000 patients so far. If you are in need of extra financial assistance during the pandemic, you can apply for a one-time \$250 Coronavirus Emergency Fund grant in your GMS account, or you can ask your social worker to apply for a grant on your behalf.

Why are you passionate about fighting kidney disease?

I am passionate about fighting kidney disease because of the patients we help. I am grateful that I do not have a personal connection to kidney disease, unlike many others. When the patients we help share their stories with me, they inspire me a great deal—they fight and stay strong, despite their daily struggles with the disease.

What is the best part of your job?

The best part of my job is hearing the gratitude our patients have for the work we do. Any time I hear from a patient, it brightens up my day. I love knowing that we make a difference in their lives, and they motivate me to work just as hard as they do in their fight every day.

What are your favorite hobbies outside of work?

I spend my free time writing, reading comic books, watching TV and playing board games. Luckily, these are all hobbies that can be done in quarantine!

Kidney Kitchen

With apples, cinnamon and the sweet flavor of molasses, these muffins taste just like fall! Enjoy them for breakfast or as a snack. Check out many more kidney-friendly recipes at 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.



Apple and Zucchini Harvest Muffins

Makes: 12 low-phosphorus, low-potassium, low-protein, medium-sodium servings



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

Recipe contributed by
The Cooking Doc®

Kidney Kitchen is supported in part by:

AstraZeneca 

**SATELLITE
HEALTHCARE**
DIALYSIS · WELLBOUND

Ingredients

1 cup whole wheat pastry flour (or all-purpose whole wheat flour if unavailable)	1/3 cup canola oil
1/2 cup all-purpose flour	1/4 cup sugar
1/4 cup ground flax seeds	1 tablespoon apple cider vinegar
1 teaspoon baking powder	1 egg
1/2 teaspoon baking soda	1/2 cup unsweetened applesauce
1 teaspoon ground cinnamon	1 tablespoon molasses
1/2 teaspoon salt	1 medium zucchini, grated (about 1 cup)
	1/2 cup shredded apple

Special equipment

Muffin baking tin

Instructions

1. Preheat oven to 425°F.
2. Coat muffin tin with nonstick cooking spray. Combine both flours, flax seeds, baking powder, baking soda, cinnamon and salt in a large bowl.
3. In a separate bowl, whisk oil, sugar, apple cider vinegar, egg, applesauce, and molasses together until well combined. Stir in the zucchini and apples.
4. Make a well in the dry ingredients and add the wet ingredients. Stir a few times to combine. Add batter to prepared muffin cups.
5. Bake for 5 minutes at 425°F and then reduce oven temperature to 350°F. Bake an additional 8-10 minutes (for a total of 13-15 minutes) until the muffins are browned on top and a toothpick comes out clean when inserted into a center muffin. Do not overcook.
6. Let cool for 5 minutes. Transfer to a wire rack to cool completely or eat while still warm.

Nutrition facts

(1 serving = 1 muffin)

Calories = 178	Fat = 8 g	Cholesterol = 15 mg
Carbohydrates = 25 g	Saturated Fat = 1 g	Sodium = 157 mg
Sugar = 7 g	Trans Fat = 0 g	Potassium = 127 mg
Fiber = 3 g	Protein = 3 g	
Calcium = 69 mg	Phosphorus = 59 mg	

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

"I have found the American Kidney Fund website, its webinars, recipes and all of its information valuable!"

"I found this webinar to be really helpful. There were some great tips I had not heard before."

"I think this webinar is a valuable resource."

"Very informative in a clear, concise manner. I learned new information and helpful tips, and it was wonderful to learn from someone who has shared our experience."



WATCH AND LEARN:

AKF webinars available on demand

AKF hosts free monthly webinars on many important topics relating to kidney disease. These webinars—and many more—can be watched at your convenience at [KidneyFund.org/webinars](https://www.kidneyfund.org/webinars). Just look for these titles in our list of webinars to watch on-demand.

Kidney Chat: Ask a nephrologist about COVID-19

The COVID-19 pandemic has been an overwhelming time full of unexpected challenges for the kidney community. Public health officials all around the world are sharing information and working together to limit the spread of the coronavirus as much as possible. There are a lot of unknowns but together, we are learning more each day. **What you'll learn:** COVID-19 and kidney disease facts, guidance for dialysis and transplant patients, and how to protect yourself and your family.

How to become a "virtual" Kidney Health Coach

Whether you're new to the American Kidney Fund's (AKF) Kidney Health Coach program or have already hosted a few sessions, we are all new to this COVID-19 world of virtual events! Here's your chance to learn how you can

help AKF spread the word about kidney disease and host kidney health education sessions from the safety of your home! **What you'll learn:** Tips and tricks for planning and hosting a virtual education session, how to select the best virtual platform, activities to make your sessions more interactive, and advice from the AKF Kidney Health Coach team.

What you need to know about nephrotic syndrome

Nephrotic syndrome is a group of symptoms that show your kidneys are not working as well as they should. These symptoms include too much protein in your urine, not enough protein in your blood, too much fat or cholesterol in your blood, and swelling. **What you'll learn:** Nephrotic syndrome causes and symptoms, the risk of nephrotic syndrome post-transplant, and the importance of follow-up visits post-transplant.

A CLINICAL RESEARCH STUDY FOR ADULTS OF AFRICAN OR CARIBBEAN DESCENT

**FIND
STRENGTH,
GIVE
STRENGTH.**

If your doctor has told you that you have kidney disease, a clinical research study may be an option for you.

Do it for you, do it for others with your condition. To learn more about a potential option for adults of African or Caribbean descent with biopsy-confirmed focal segmental glomerulosclerosis (FSGS), talk to your doctor and visit FSGSKidneyStudy.com. Compensation for study-related time and travel, as well as travel assistance, may be available.



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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:

- Navigating COVID-19 reopenings
- FSGS and the APOL1 gene
- AKF staff spotlight
- Fall 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.



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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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Waltham, MA 02451

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