



Tamara Y. W., Athens, Ga.
AKF Ambassador

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AKF in Action

Fighting kidney disease and helping people live healthier lives.

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Tackling the unknown causes of kidney disease

The most common causes of kidney disease are diabetes and high blood pressure, but did you know that the cause of kidney disease remains a mystery for 5% to 20% of people who have it? Through its Unknown Causes of Kidney Disease Project, the American Kidney Fund (AKF) has been leading the kidney community in addressing underdiagnosed and misdiagnosed causes of kidney disease and coming up with ways to improve patient care through innovation in research, accurate diagnoses and treatment.

On July 27, 2021, AKF released its *Roadmap for Addressing the Unknown Causes of Kidney Disease*, a comprehensive guide that outlines

how to improve diagnosis of the root causes of kidney disease. The *Roadmap* summarizes the barriers to identifying the causes of kidney disease, the challenges that not having a clear diagnosis cause in patients' lives, and the potential solutions that can improve diagnoses, ultimately improving care and slowing the progression of kidney disease. The *Roadmap* was developed based on expert insights that were discussed during AKF's Unknown Causes of Kidney Disease Summit in December 2020.

AKF's *Roadmap* identifies four overarching solution areas:

- Advocating for widespread and equitable insurance coverage of tests, including genetic tests, to help understand and diagnose kidney disease
- Increasing providers' interest and awareness about the range of possible causes of kidney disease, through education and incentive structures
- Educating patients about kidney disease and testing in an effective,

culturally competent way, and empowering them to advocate for an accurate diagnosis

- Based on the evidence available, encouraging the development of national standards related to when and how genetic testing can be useful and applied

AKF believes that everyone with kidney disease should have as much information about their health as possible so the best treatment decisions can be made. If you do not know what caused your kidney disease, you can talk to your doctor about available tests and what your insurance will cover.

You can learn more about AKF's Unknown Causes of Kidney Disease Project, read the *Roadmap* and watch a panel discussion about it at KidneyFund.org/UCKD.

The Unknown Causes of Kidney Disease Project is supported by Leadership Sponsors Natera, Otsuka America Pharmaceutical, Inc., Sanofi Genzyme and Vertex, and Champion Sponsors Alexion and Traverre.



Enclosed in this newsletter, you will find a card from someone in AKF's community. We hope their message of support brightens your day!



KidneyNation spotlight: Gaming for a cause

Tracey Schrader has been playing video games since she discovered Atari at age seven. These days, she enjoys losing herself in Minecraft. “It’s such a pretty world,” she says, “I just love it.” But livestream gaming not only gives Tracey a chance to laugh and unwind with friends—it also helps her raise money for AKF’s programs and services, which in turn help people with kidney disease like her.

Tracey is the current recordholder for the most money raised through livestreaming on KidneyNation, AKF’s do-it-yourself fundraising program. AKF helps people organize their own fundraising “streamathons,” and 97 cents of every dollar they raise goes right back to helping the kidney community. Tracey’s latest fundraiser brought in over \$1,300, exceeding its goal.

Before Tracey got a kidney transplant, she used to receive financial assistance from AKF to help her afford the high costs of dialysis under two insurance plans. She had been a nanny for 13 years, but couldn’t continue her work while undergoing intensive dialysis treatments multiple times a week, which left Tracey and her husband, Frank, with only one income. Tracey says she doesn’t know what they would have done without AKF’s help if they had to pay out-of-pocket for her full medical costs.

When Tracey found out about KidneyNation’s Streamers vs. Kidney Disease events, she “felt very passionate” and knew she had to participate. She worked hard to organize her own streaming event and brought in guests for her fundraiser, many of whom couldn’t afford to donate large amounts, especially during the financial strain of the COVID-19 pandemic. She says she’s happy to fundraise “dollar-by-dollar,” knowing that even one donated dollar per person goes

a long way. “I was like a bulldog,” she said, speaking of her determination to see the fundraiser through.

Tracey’s own battle with kidney disease and her path to getting a transplant wasn’t easy. She spent over seven years on dialysis, starting at age 39, and was rejected by two hospitals for a kidney transplant after being deemed a high-risk patient. At one point, she gave up hope that she’d ever receive a kidney.

“My family and friends got me through everything,” she says, remembering the dedication of her husband, who she relied on for emotional and financial support, and who even sat with her for hours during many of her dialysis sessions after a long day’s work. Her supportive friends would come over to help her keep her house clean and stocked with groceries. Her mother, Ursula, and sister, Lisa, were also there for her emotionally and pitched in to help with treatments. Tracey says that without Lisa, who always encouraged her to stay on the kidney transplant waiting list and not give up hope, she “wouldn’t be alive today.”

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When Tracey finally received the call letting her know that it was her turn for a transplant, she didn’t believe it at first. The staff members at her dialysis center learned of the news before she did, and when several of them congratulated her, she didn’t know what they meant. “You were accepted!” they said. “We got the fax this morning.”

Because of heart issues, Tracey’s transplant was considered a little high risk, but her doctors and family members encouraged her to go through with the surgery. Her transplant was successful, but it took nearly eight months before she felt well enough to resume everyday life. “It was a long process,” she says, “but I got there.”

To learn more about AKF’s KidneyNation program and start your own fundraiser, visit [KidneyNation.org](https://www.kidneyfund.org).

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

"Webinars AKF offers are very informative, easy to understand and practical. I have not been able to find such information in another forum."

"It's nice to hear about different topics that doctors don't have time to address."

"Very informative, down-to-earth information that is easy to understand and apply."

"I enjoyed this webinar and thought it was very helpful and well-presented."



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).

Potassium & CKD: How to manage potassium long term

Healthy kidneys help keep the right amount of potassium in your body. When you have kidney disease, your potassium levels can get too high, which can have serious consequences. Even though potassium comes from the foods you eat, there are also medicines called binders that you can take to help you control potassium. **What you'll learn:** How potassium binders can help you control potassium long-term, how to use food labels to track potassium in the foods you eat, and tips for sticking to your potassium management plan.

Clinical trials and kidney disease

Clinical trials are research studies that test the effectiveness of new treatments or other medical procedures. Participating in a clinical trial not only contributes to science and the development of

new medicines or treatments, but could actually improve your health and quality of life. **What you'll learn:** What clinical trials are and how participants are protected, why diversity in clinical trials matters, and benefits of clinical trials for science and your health.

Estudios clínicos y enfermedad renal (en español)

Los ensayos clínicos son estudios de investigación que prueban la efectividad de los nuevos tratamientos u otros procedimientos médicos. La participación en un ensayo clínico no solo contribuye a la ciencia y al desarrollo de medicinas o tratamientos nuevos, sino que también podrían hacer que mejores tu salud y calidad de vida. **Qué aprenderá:** Qué son los ensayos clínicos, cómo se protege a los participantes y por qué es tan importante la diversidad de participantes en los ensayos clínicos.



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).

AKF staff spotlight



Name: Lindsay

Hometown: Ashburn, Va.

What do you do at AKF?

I'm the associate director of state policy and advocacy at AKF. Our state team helps to pass laws and regulations that will better

the lives of people with kidney disease and living organ donors all over the country, as well as prevent bills that would harm the kidney community from becoming law.

Join us in the fight against kidney disease by becoming an AKF Ambassador at KidneyFund.org/ambassadors.

What is your connection to kidney disease?

The devastating effects of kidney disease are personal to me. Like many Americans, I have a family member—my grandmother—who is currently navigating the health care system and the kidney disease patient journey. This motivates me to not only work tirelessly to move the needle for those close to me, but also for the other 37 million people with kidney disease across the country,

and their families, who are going through the same experience.

Why are you passionate about fighting kidney disease?

To say that I'm a lifelong advocate for finding cures and treatments for diseases and being a voice for those who need one is an understatement. Many of my family members have worked in health care, so watching the impact they have had on others' lives has inspired me to pursue my education and professional experience in policy, communications and advocacy.

What is the best part of your job?

Passing legislation that improves lives and gives hope to those fighting kidney disease. This year, AKF led the introduction of legislation to protect living organ donors and seven states passed these laws! Now, there are 20 states total that have prohibited life, disability and long-term care insurers from discriminating against people who choose to give the gift of life. I'm looking forward to expanding the number of states that protect living organ donors in 2022!

Kidney Kitchen

Flavorful, spicy and delicious, these stuffed mushrooms are great for a vaccinated get together or as a side dish. 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.



Indian Inspired Stuffed Mushrooms

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

Prep time: 20 min
Cook time: 12 min

Recipe contributed by FamilyCook Productions

Ingredients for mushrooms:

8 (144 grams) white mushrooms
1 teaspoon olive oil
1 teaspoon balsamic vinegar
1 pinch black pepper, freshly ground

Ingredients for filling:

½ cup cheddar cheese, shredded, low sodium
3 tablespoons red bell pepper, minced
3 tablespoons red onion, minced
1½ tablespoons cilantro, minced
2 teaspoons jalapeño pepper, minced
1 pinch sea salt
¾ teaspoon coriander seeds, ground
¼ teaspoon paprika



Tip: Try different cheeses, such as mozzarella, in place of the cheddar to change up the flavor.

Directions for mushrooms:

1. Preheat oven to 350°F.
2. Line a baking sheet with parchment.
3. Clean mushrooms with a damp cloth. Remove the stem by pulling gently to hollow the mushroom cap.
4. Combine mushrooms, olive oil, balsamic vinegar, and pepper into a small mixing bowl. Mix well.

Directions for filling and assembly:

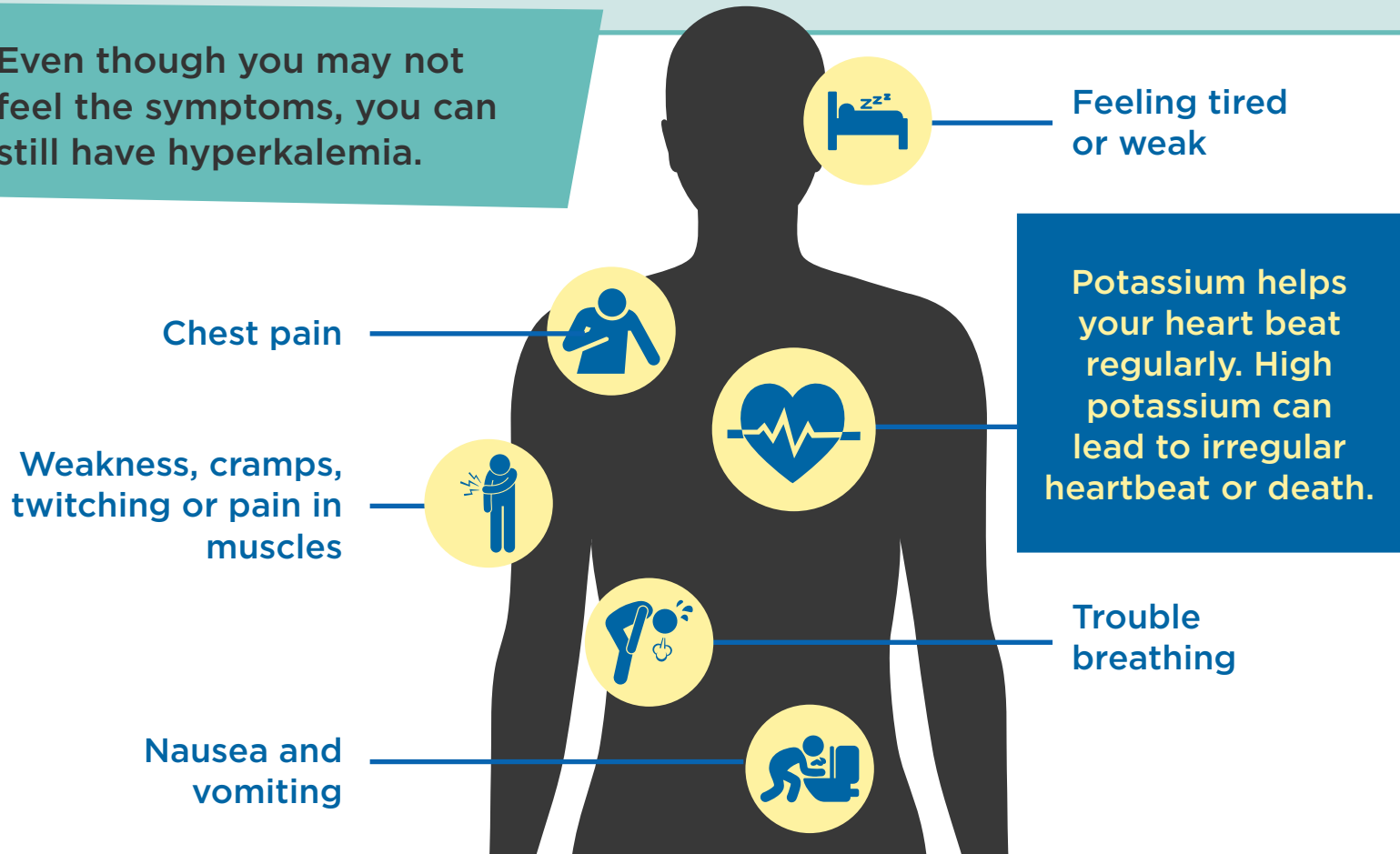
1. Combine cheese, bell pepper, onion, cilantro, jalapeño pepper, salt, coriander seeds and paprika into a small mixing bowl.
2. Divide filling into quarters, divide quarters in half to make 8 equal parts. Stuff each coated mushroom with 1/8 of the filling.
3. Place the coated mushrooms on the baking pan. Bake the mushrooms for 12 minutes or until sufficiently browned and cooked.
4. Remove from the oven and cool for 5 minutes.

View full nutrition information at KidneyFund.org/kitchen.

Hyperkalemia (high potassium) and kidney disease

Hyperkalemia is an ongoing condition that can be dangerous. It happens when your kidneys cannot remove the extra potassium in your body.

Even though you may not feel the symptoms, you can still have hyperkalemia.



Manage
your
potassium
long-term.



Ask your
doctor about
your potassium
levels.



Take
potassium
binders as
prescribed.



Ask your dietitian
how to track your
daily potassium
intake.

Donor derived cell-free DNA: A new kidney transplant monitoring method

By Silas Prescod Norman, M.D., M.P.H.,
American Kidney Fund Board of Trustees Chair-Elect

When you are living with a kidney transplant, it is important for your doctor to consistently monitor how well your new kidney is functioning to ensure that you have the best health outcomes as possible.

What are the current limitations to post-transplant kidney monitoring?

Currently, the main way nephrologists like me monitor your new kidney is by measuring your serum creatinine through a blood draw. Monitoring helps us know if your kidney function is stable and alerts us if there are problems. Although easy and inexpensive, creatinine is not a very sensitive marker for identifying early kidney injury. You may have significant injury to your transplanted kidney before your creatinine is elevated, and treatments may not be as effective. Ideally, there would be a better way to monitor your kidney closely to catch problems earlier.

The gold standard for diagnosing problems with your transplant is through a kidney biopsy. During the biopsy procedure, we insert a small needle into your kidney and take out a small sample for examination under a microscope. The biopsy is very informative, but it's an invasive procedure that comes with a small risk of bleeding after the procedure. Because of this, the biopsy is not ideal for ongoing kidney monitoring. Ideally, what we would like is a non-invasive but highly informative test to let us know if there are problems happening with your transplant as early as possible. There are some new tests on the market that can help address kidney biopsy limitations.

What are these new tests for kidney monitoring and how do they work?

The new kidney monitoring tests use a simple blood draw and take advantage of the fact that most cells in your body contain DNA. DNA contains the information that helps define you as uniquely you. Your transplanted kidney also has DNA in its cells from your donor. When there is damage to your transplant, like rejection, cells

are injured and DNA from the kidney is released into your blood. This DNA that now circulates through your body is called cell-free DNA (cfDNA). There are new blood tests that can tell the difference between your DNA and your kidney donor's DNA (donor derived or dd-cfDNA). If there is more dd-cfDNA circulating than normal, this is an indication that you may have a kidney injury, including rejection. These tests are more accurate than just checking serum creatinine, and because these tests only require a blood draw, they allow your transplant center to monitor your kidney health very closely.

How are the tests used?

These tests are used in two ways, for surveillance and to help decide if you do need a kidney biopsy.

For surveillance, when you feel well and your creatinine is doing well, these tests can reassure you that there is no subtle, unrecognized damage or rejection going on with your transplant. In addition, if your creatinine is normal but your dd-cfDNA is elevated, this may be an early warning sign for your transplant doctor that they need to do more investigation, sometimes including a kidney biopsy, to catch problems early and allow for the best treatment before there is a lot of kidney damage.

These tests may also help avoid unnecessary kidney biopsies. Typically, if your creatinine is elevated for unclear reasons, you may be asked to have a kidney biopsy to exclude the possibility of rejection, infection or other acute damage to your transplant. But now, if you have elevated creatinine but a normal amount of circulating dd-cfDNA, your transplant provider can feel comfortable that most of the time this means there is no damage to your transplant and they may watch you closely, rather than perform an invasive biopsy.

Are the tests accurate?

Yes. A normal test almost all the time means there is no rejection happening in your kidney. An abnormal result means there is a good chance you are experiencing rejection. Because these tests are simple blood draws, many transplant doctors use them every 1-3 months per year for the first few years after your surgery to know how your new kidney is performing. These tests also give your transplant center a good way to monitor your kidney long term.

The dd-cfDNA tests are a significant improvement to the kidney monitoring tools we had before. These tests can help you get as many healthy years as possible out of your kidney transplant.

Continued on next page.

Are these tests covered by insurance?

The tests are covered by Medicare and many private insurance companies and may be a great complement to your overall transplant care. If you are facing any out-of-pocket expenses related to these types of tests, the American Kidney Fund (AKF) may be able to help with our Post-Transplant Testing Program.

What is AKF's Post-Transplant Testing Program?

AKF's post-transplant testing program can assist you with a one-time grant of up to \$1,200 for out-of-pocket

expenses, like co-pays and deductibles. Financially eligible transplant recipients can apply through AKF's Grants Management System (GMS). For questions, either send us a message through GMS or email registration@kidneyfund.org.

Dr. Silas Prescod Norman is a nephrologist at the University of Michigan Ann Arbor, overseeing the Transplant Multidisciplinary Ambulatory Care Units which see more than 18,000 patient visits annually. He is chair-elect of AKF's National Board of Trustees.



POST-TRANSPLANT TESTING Program

Have you received a kidney transplant within the last 10 years? Talk to your doctor about the new and less invasive donor-derived cell-free DNA tests that can detect early damage or rejection in your transplanted kidney. The American Kidney Fund (AKF) is providing financial assistance to cover these innovative new blood tests that offer ongoing monitoring of the health of your transplanted kidney without the need for a kidney biopsy. The tests are accurate and can be done every few months, giving your transplant team a good way to monitor your transplant long term.

ELIGIBILITY REQUIREMENTS:

- Up to 10 years post-transplant
- Annual income up to 500% of Federal Poverty Level
- 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 AKF's Patient Services Department at registration@kidneyfund.org or 1-800-795-3226.



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Suite 300
Rockville, MD 20852
800.638.8299

KidneyFund.org

Questions about the COVID-19 vaccines?
We've got you covered at [KidneyFund.org/vaccine](https://www.kidneyfund.org/vaccine).

WHAT'S INSIDE:

- Tackling the unknown causes of kidney disease
- Gaming for a cause
- Kidney Kitchen recipe
- New kidney transplant monitoring method



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:

Fresenius Medical Care North America
920 Winter Street
Waltham, MA 02451

Patents apply, visit www.fmcna.com/patents

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