

WINTER 2021 | VOL. 6.4

AKF in Action

Fighting kidney disease and helping people live healthier lives.


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Receiving AKF grant assistance via debit cards and direct deposit

Ensuring that people with kidney disease are able to afford their medical expenses has been at the heart of the American Kidney Fund's (AKF) mission since our founding 50 years ago. Our need-based programs help people with many expenses related to health care, and we are always seeking to enhance and streamline how we provide our grants.

If you are currently receiving your AKF grant payments by check, did you know that there are other convenient payment options you could choose from? AKF offers payments by debit cards and automated clearing house (ACH) direct deposits, too.

Debit card payments

While debit cards have been a payment option for our Health Insurance Premium Program (HIPP) for many years, you can now receive prepaid debit cards for more of our financial assistance programs. Payments for our Safety Net and Disaster Relief Program grants will now be provided by non-restricted, prepaid debit card or by direct deposit only.

This debit card option is intended to remove barriers when it comes to

accessing your financial assistance from AKF, decrease mailing times and allow for expanded online use.

ACH direct deposit payments

ACH direct deposits are a safe, secure way to receive your AKF grant payments. With ACH direct deposits, you receive your grants faster and avoid any potential issues or delays with postal delivery. This payment method is available for some HIPP grants, as well as Safety Net, Post-Transplant Testing Program and Disaster Relief Program grants.


To receive your grant payment through ACH direct deposit, you must:


1. Have your bank account number and your bank's routing number available
2. Have a valid email address saved in your Grants Management System (GMS) profile


Please make sure your bank account and routing numbers are correct when entering this information in your GMS account. An incorrect number will create a delay in processing this information with your bank.


Questions?


If you have any questions about AKF's financial assistance programs or need help using your GMS account, please contact AKF's patient services department for help:

 **Phone:** Call us at **1.800.795.3226** from 9 a.m. to 5:30 p.m. ET Monday through Thursday, and from 9 a.m. to 3 p.m. ET on Friday. Please call during business hours to speak with a live representative. To protect your privacy, voicemails are not accepted or responded to.

 **GMS Assist:** Visit **GMSassist.com** to make a phone appointment to speak to us at a time that is convenient for you.

 **GMS:** Message us through your GMS account at **gms.KidneyFund.org**. Be sure to also check the information and FAQ sections of your account for up-to-date information.

 **Online:** Visit **KidneyFund.org** to learn more about AKF's financial assistance programs.

 **GMS registration issues:** Email us at **registration@KidneyFund.org**.

Visit [KidneyFund.org](https://www.kidneyfund.org) to learn more about clinical trials and test your clinical trials IQ.



Thank you to our corporate members for making our work possible in 2021!





Ruth Scott

Crystal Scott

Advocacy spotlight: Mother and daughter Ambassadors advocate for kidney legislation

When you think of mother-daughter activities, a trip to visit your elected officials to advocate for kidney health legislation probably doesn't cross your mind. But that is exactly what Crystal and Ruth Scott did during AKF's Kidney Action Summit earlier this year. Although the two live several states apart—with mother Ruth in New York and daughter Crystal in Maryland—becoming AKF Ambassadors has been a way for them to connect as they fight to improve the lives of those living with kidney disease, like Crystal.

During the Kidney Action Summit, both Ruth and Crystal met with their respective states' senators to advocate for the federal Living Donor Protection Act and the Jack Reynolds Memorial Medigap Expansion Act. Although Ruth became an AKF Ambassador more recently, her background as the first city-wide councilperson of color for Rochester, New York meant she was very comfortable speaking with her members of Congress.

"Having had those connections, she's a far more forceful advocate with members of Congress because she knows how to ask the questions in a way that holds them accountable," Crystal said about her mom. "And that's been really helpful."

For her part, Ruth said it was a fun experience to talk to her representative during the Kidney Action Summit since she already knew him from her days as a politician. "It was interesting to see him in a different light and to see the senators be so engaged," she said. All her members of Congress "assured us that they were totally in sync with making sure that these bills got passed, so that was nice." (One of Ruth's senators,

Senator Kirsten Gillibrand, is one of the main sponsors of the Living Donor Protection Act.)

Like her mother, Crystal is fortunate that her Congressman, Jamie Raskin, is "all-in" on supporting legislation that improves the lives of those living with kidney disease. She met with both him and Senator Chris Van Hollen during the Kidney Action Summit. Although it was her first time meeting with Senator Van Hollen, she had met with Rep. Raskin at several previous events, including a breakfast Rep. Raskin hosted. Both mother and daughter agree that attending meet-and-greet events, like breakfasts with your members of Congress, is helpful for promoting your cause when it comes time to advocating during events like the Kidney Action Summit.

"You keep trying," advised Crystal. "You keep trying to get on their calendar. You keep trying to meet them. You go to the spaces where they're going to be and get near them."

"Building up that relationship and maintaining that relationship means that I'm really able to call on [Rep. Raskin] as new legislation comes up or bills come up that may be restrictive for kidney care or may need his sponsorship to expand those things," said Crystal. "It's always good to have a relationship that actually is forged and becomes a friendly relationship where you can be candid about [the issues]."

As a former city councilmember, Ruth also knows firsthand the importance of building relationships with your elected officials. From her experience, she would advise you to research and prepare for your meetings. That way you will be confident in your meetings and your elected officials will know how serious you are about the issues. "Those things build relationships," said Ruth, "and it's relationships you want to build in order to have any influence on a representative."

Both Crystal and Ruth describe their family as "political" and expressed feeling very comfortable talking to elected officials. They recognize that not everyone has the same background as they do, but hope that those who are not as experienced talking to representatives will persist.

"You keep trying," advised Crystal. "You keep trying to get on their calendar. You keep trying to meet them. You go to the spaces where they're going to be and get near them."

Continued on next page.

Advocacy spotlight, cont.

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Sometimes you may not be able to meet directly with your representative or senator. Instead, you may be offered a meeting with a member of their staff. Crystal says you should not “get discouraged if you meet with a staff member” because that staff member may be the person who has the connection to kidney disease that will make your story relatable to the elected official.

Crystal has been that connection for staff members. A friend of hers works for an elected official in another state, and Crystal’s experience with kidney disease made that friend fight a little harder for legislation that would improve the lives of people with kidney disease in her state.

Crystal was diagnosed with kidney failure in February 2012. She immediately started peritoneal dialysis, which she continued on and off for six and a half years before receiving a kidney transplant. Crystal became an AKF Ambassador about ten years ago because she saw the “opportunity for me to give back to the organization that has helped me out.”

About two years ago, Crystal encouraged her mother to also become an Ambassador. In Ruth’s case, she joined because she wanted to better understand what her daughter was going through— “it gave me some sense of what Crystal might be going through and a little bit of understanding about how I might be of help,” she said.

“It’s been a good time,” Crystal said of having her mother as a fellow Ambassador. “She’s been in on the on the Ambassador meetings and it’s been really great. I’m excited and happy that she’s gotten engaged.”



Did you know that anemia and kidney failure often go hand in hand? Most people with kidney failure who are on dialysis have anemia, and people living with a kidney transplant are also at higher risk. To learn more about the anemia-kidney disease connection and how to get your questions answered by your care team, visit our YouTube page at [YouTube.com/KidneyFund](https://www.youtube.com/KidneyFund).

Anemia is a common complication of chronic kidney disease or CKD



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Managing of anemia of chronic kidney disease (CKD) can boost your health and quality of life



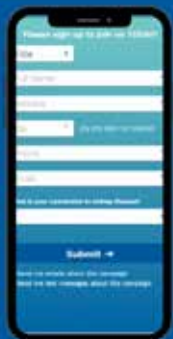
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Treatment options



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MOBILE ADVOCACY NETWORK



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Real participant reviews of Kidney Action Week sessions:

“Really empowering session! Thank you for providing such great resources for the kidney community.”

“Thank you for this valuable presentation! It answered many of my questions.”

“Thank you for doing this. Dad is on dialysis, and I have kidney disease as well. Much appreciated.”

“Thank you. This has been the best session I have attended.”



WATCH AND LEARN:

Sessions from AKF's Kidney Action Week

A KF's second annual Kidney Action Week in September brought together patients, medical experts and advocates for 14 virtual sessions on healthy living in the face of kidney disease, with an emphasis on confronting health disparities. If you missed any of these engaging, informative sessions, you can watch them at your convenience at [KidneyActionWeek.org](https://www.kidneyactionweek.org) or in our 2021 Kidney Action Week playlist at [YouTube.com/KidneyFund](https://www.youtube.com/KidneyFund). Here were some of the week's highlights:

Know your kidney health care team: Effective communication for the best health outcome

Effective communication and shared decision-making is a key component to patient-centered care. In this session, experts and a patient gave advice on how people with kidney disease and caregivers can actively work with their doctors and treatment team for improved outcomes. **What you'll learn:** How to become empowered to serve as your own advocate and get answers to questions about your care.

Kidney disease & mental health

Many people with kidney disease are also managing depression, anxiety disorders and other mental health conditions. The COVID-19 pandemic has made this problem even worse through economic struggles, fears of contracting the virus and social isolation. **What you'll learn:** What you can do to maintain your mental health and thrive with kidney disease.

The kidney transplant process: What you need to know

The living kidney donor process can seem overwhelming for both the kidney donor and recipient. In this session, panelists talked about the transplant process, what it entails and why we are still seeing living donor disparities in Black and Hispanic/Latino people with kidney disease. **What you'll learn:** Advice for overcoming these barriers and answers to frequently asked questions about the transplant process.

Kidney Action Week was made possible by the generosity of sponsors Boehringer Ingelheim/Lilly, Otsuka America Pharmaceutical, Inc. and US Renal Care, as well as session sponsors AstraZeneca, Alexion Pharmaceuticals, GSK, Horizon Therapeutics plc, Natera, Sanofi Genzyme, Travere and Vertex Pharmaceuticals.

AKF staff spotlight



Name: Carlos

Hometown: Bogotá, Colombia

What do you do at AKF?

I'm AKF's director of health initiatives. I work with our health initiatives team on programs and projects influencing health

disparities in access to kidney transplants, home dialysis, clinical trial involvement and prevention and awareness of kidney disease.

I recently worked with team members across AKF on our second annual Kidney Action Week. We were able to expand the virtual program from last year and offer more educational sessions across the spectrum of kidney disease. We received some really great feedback from people with kidney disease and their caregivers, and hope to use that feedback to continue to grow the program to provide even more resources and tools for people to live their healthiest lives!

What is your connection to kidney disease?

I have to be honest—prior to working at AKF, I was fairly oblivious about the devastating effects of kidney disease and who in my social network it could be affecting. Due to my work at AKF, I have now become vocal about kidney disease with people in my social networks. Multiple of my family members and friends have talked to me about their personal journey with kidney disease, or about the journeys of others they know. The fact that most of them only speak about it with me privately, and don't feel comfortable talking openly about their journey, demonstrates to me how

much work we must do to educate the public and remove the stigma associated with kidney disease.

Why are you passionate about fighting kidney disease?

AKF's work fighting health disparities is particularly important to me. Based on my own life experiences, I became a social worker to help uplift people and communities so they have the best opportunities to live their lives to the fullest. Making people aware of the often devastating effects of socioeconomic disparities, working to improve equality in kidney care and collaborating with the entire AKF team to improve the quality of life for all people gives me a wonderful sense of pride and purpose.

What is the best part of your job?

Feedback from the kidney community about the positive impact of AKF's programs is something I greatly value. Working on Kidney Action Week provided me the opportunity to work directly with AKF Ambassadors, which I had not done much of previously in my job. In meeting and talking with them, I was honestly amazed about how positive and caring they are about everyone who has kidney disease. Our Ambassadors' hope shines through when you chat with them, and their willingness to help with our awareness and educational campaigns is inspiring!

What are your hobbies outside of work?

I am an avid sports fan and love watching football and fútbol (soccer)! More recently, my favorite hobbies are spending time on walks and hikes with my wonderful wife, my incredible 16-month-old son and my crazy and loveable 109 lbs., 15-month-old, Alaskan Malamute.

GRATITUDE

OUR HEARTS ARE FILLED WITH **GRATITUDE**. THANK YOU FOR YOUR SHARED COMMITMENT TO OUR **MISSION** AND FOR BEING THE REASON BEHIND THE WORK WE DO EVERY DAY.

Kidney Kitchen

Here is a delicious recipe that uses all parts of the cauliflower—including the stem and leaves—to reduce food waste. 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.



Zero Waste Creamy Cauliflower Carrot Ginger Soup

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



Prep time: 10 min
Cook time: 20 min

Recipe contributed by FamilyCook Productions



Tip: Make your own no-sodium vegetable stock by saving vegetable scraps in a plastic bag in the freezer until you accumulate at least a 1-quart bag full. Then cook in water and voilà—you have stock for this recipe. You can also freeze in 2 cup portions for future use.

Ingredients:

1 medium (558 grams) cauliflower, whole with core, cut in florets and chunks, with the stem and leaves
2 tablespoons coconut oil
¼ teaspoon sea salt
¼ teaspoon black pepper, freshly ground
1 teaspoon cumin seeds, ground
1 teaspoon coriander seeds, ground
1 teaspoon fennel seeds, ground
¼ teaspoon turmeric powder
2 bay leaves

1 large (72 grams) carrot, chopped
3 stalks (120 grams) celery, chopped
2 inches (8 grams) ginger root, peeled, grated, and chopped
¼ cup red lentils
3 cups vegetable stock, low sodium
1 lime, juiced and zested
1 tablespoon olive oil for garnishing
¼ cup Italian parsley, chopped

Special Equipment:

Food Processor/Blender

Directions:

1. Chop the leaves and stalk/stem of the cauliflower into approximately 1-inch pieces.
2. Heat 1 tablespoon coconut oil in a large pot on medium-high heat.
3. Sauté the cauliflower stalks with ½ teaspoon each of salt and black pepper until they are golden (about 4-5 minutes). Set aside.
4. Combine the ground cumin, coriander, fennel seeds, turmeric, with the remaining ¼ teaspoon salt and pepper in a ramekin and mix well.
5. Add to the same pot used to sauté the cauliflower stem and leaves and toast spices and bay leaves over medium-low heat until they become fragrant (about 4 minutes).
6. Add remaining tablespoon of olive oil, along with the carrots, celery, and ginger, mixing to coat with the spices. Sauté for another 4 minutes on medium heat.
7. Add the cauliflower florets, cauliflower stalks, red lentils and the stock to the pot. Increase heat to boil then reduce to a simmer over medium heat for about 8 minutes or until the cauliflower is tender.
8. Remove the bay leaves. Puree the soup with the lime juice in batches in a blender or with an immersion blender.
9. Serve in bowls, topping each serving with the sautéed cauliflower leaves, chopped parsley and drizzle with olive oil.

Nutrition facts (1 serving=¼ of recipe)

Calories = 197

Sugar = 5 g

Carbohydrates = 7 g

Fiber = 6 g

Calcium = 74 mg

Fat = 12 g

Saturated Fat = 6 g

Trans Fat = 0 g

Protein = 7 g

Phosphorus = 110 mg

Cholesterol = 0 mg

Sodium = 311 mg

Potassium = 518 mg

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

FIRST30

- 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





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Help us fight kidney disease.
Text **KIDNEY** to **52886** to join our mobile advocacy network.

WHAT'S INSIDE:

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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).

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Fresenius Medical Care North America
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Waltham, MA 02451

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