

Evan Dame North Brentwood, MD AKF Ambassador

American Kidney Fund

WINTER 2025 | VOL. 10.4

AKF in ACTION

Fighting kidney disease and helping people live healthier lives.

Connect with us:

f /AmericanKidneyFund

@AmericanKidneyFund

X @KidneyFund

X @AKF_Advocacy

@KidneyFund

Fighting on all fronts in 2025

e put people like you at the center of everything we do at the American Kidney Fund. Here are some of the initiatives we undertook in 2025 to fulfill our mission:

Advocacy

In May, AKF welcomed 30 Ambassadors—kidney patients, caregivers and living kidney donors—from 18 states and the District of Columbia to Capitol Hill in Washington, D.C. for our 2025 Kidney Action Summit. Ambassadors had 58 congressional meetings, where they asked lawmakers to support legislation to help protect living organ donors and to safeguard Medicaid, a lifeline for many people living with kidney disease.

AKF returned to Capitol Hill in September, bringing 25 advocates from 16 states for our third annual Rare Kidney Disease Advocacy Day. Members of AKF's Rare Kidney Disease Action Network and AKF staff held 49 meetings urging lawmakers to support legislation that would improve health care services for people with rare kidney disease, increase awareness of rare kidney disease, ensure living donors can take time off work to donate an organ and protect living donors from insurance discrimination.

We also hosted our third annual Patient Access Initiative Summit in November in Washington, D.C. The initiative and summit are integral to AKF's commitment to addressing barriers to preventive services and quality treatment and identifying policy solutions that will improve health care access. This year's summit focused on innovation and highlighted new technologies that can strengthen every stage of kidney care, from early detection to post-transplant management. The increasing role of artificial intelligence (AI) in kidney health—specifically how to use AI responsibly to promote equity and achieve better patient outcomes—also was a focus. Attendees included kidney patients, health care providers, public policy experts and representatives from biopharma companies.

Kidney disease education and programs

AKF hosted several educational events in 2025, including:

 Kidney Action Week®, the only free, online conference in the country where people with kidney disease, health professionals, caregivers, advocates and other kidney community members gather virtually to learn and connect. A highlight of Kidney Month, Kidney Action Week featured educational sessions on topics such as rare kidney disease, kidney disease management, dialysis, transplant and living organ donation and clinical research and innovation. Recordings of the 2025 Kidney Action Week sessions, which have so far been viewed more than 100,000 times, can be found on youtube.com/@kidneyfund.

- Unknown Causes of Kidney Disease Summit. This year's summit focused in part on education and community outreach in rural and underserved areas and was attended by health and industry leaders and patient advocates. The summit is a critical part of AKF's Unknown Causes of Kidney Disease Project®, which works to expand access to genetic testing, reduce barriers to quality care, engage providers and empower patients. An estimated 15% of people with kidney disease don't know the cause of their disease, according to an AKF survey of health care professionals.
- Dialysis at Home, a free, one-day virtual program that is part of AKF's Kidney Health for All® initiative. Dialysis at Home includes educational sessions featuring patients, advocates, care partners and health professionals who discuss options, benefits, challenges and other considerations surrounding home dialysis.

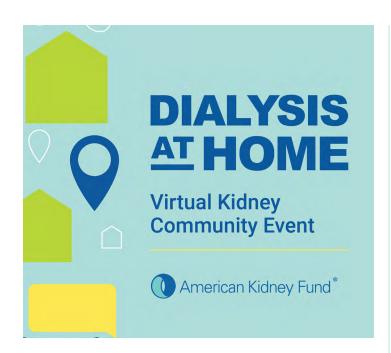
Charitable assistance

So far this year, AKF is proud to have provided financial assistance related to lifesaving treatments to more than 57,000 people living with kidney failure through our Health Insurance Premium Program, including helping more than 1,400 people get off dialysis by providing financial assistance that makes transplants possible. In addition, we provided direct financial assistance to over 13,000 people through our Safety Net Program and activated our Disaster Relief Program to assist patients impacted by the Southern California wildfires and the Central Texas floods.

AKF has also provided 140 grants in 2025 to living kidney donors as part of our Living Donor Assistance Program $^{\text{TM}}$.

If you are interested in working with AKF, visit kidneyfund.org/get-involved to find out how to become a Kidney Health Coach®, advocate for kidney patients and/or fundraise for AKF.

AKF's 'Dialysis at Home' helps kidney community members make informed decisions about options



n Nov. 20, members of the kidney community came together for AKF's fourth annual Dialysis at Home virtual event. With the theme "Your Path Toward an Informed Decision," this year's event featured educational sessions on a variety of topics, including adapting to life on home dialysis, recognizing mental health needs when dialyzing at home, increasing access to home dialysis in underserved communities, advancements in home dialysis care and building a home dialysis community.

Here are highlights from three of those sessions, in case you missed the event:

Your mental health matters: Recognizing your needs and finding support

Transitioning from in-center dialysis to home dialysis can change your social support network and have an impact on your mental health. In this session, Lukman Adebayo, manager of strategic social work services at Fresenius Medical Care, and Lupita Ayala, AKF Ambassador and Kidney Health Coach®, shared practical tips and resources to help you recognize your emotional needs and why it is so important to take care of your mental and emotional health while dialyzing at home. The speakers also gave advice on how to stay positive and how to find the right kind of help and support.

Home dialysis for all: Building trust and access in underserved communities

Despite the clinical and lifestyle benefits it can bring, home dialysis use is lower within Black/African American, Hispanic/Latino and rural communities. Dr. Matthew Sinclair, a nephrologist at Duke University; Dr. Miriam Vélez-Bermúdez, a postdoctoral fellow at the University of New Mexico; and Kristal Higgins, AKF Ambassador and former dialysis patient, discussed factors that lead to lower home dialysis usage within underserved communities. These factors include inadequate patient education and training, lack of trust, limited resources, geographic barriers and misinformation. The speakers discussed health disparities that impact these communities and shed light on the importance of creating medical education that is culturally appropriate, as well as strategies and resources that currently exist for these underserved populations.



Advancements in home dialysis: A look ahead

In this session, Dr. Eric Weinhandl, vice president of epidemiology at DaVita Clinical Research, and Dr. Nupur Gupta, a nephrologist at Indiana University, spoke about how innovation is transforming the way people receive dialysis care and the exciting advancements that are on the horizon for home treatment. The speakers highlighted the latest tools and technologies and discussed how these advancements can improve care, enhance someone's quality of life and help reduce barriers to home treatment.

To view all Dialysis at Home sessions, visit youtube.com/@kidneyfund. You can also download AKF's home dialysis resources, available at KidneyHealthforAll.org.

AKF's third round of Kidney Health Coach Health Equity Grant awardees are empowering community members to take charge of their kidney health

his year, AKF launched its third round of the Kidney Health Coach® (KHC) Health Equity Grant program to help expand the reach and impact of KHC by empowering organizations and coaches across the country to reach at-risk communities and spread health messaging in chronic kidney disease (CKD) prevention and management.

Here is an overview of how some of the organizations that received KHC grants have been using their funds.

Asociación Puertorriqueña de Diabetes San Juan, Puerto Rico

"The Asociación Puertorriqueña de Diabetes is a non-profit dedicated to empowering individuals and communities through education, prevention and support for those living with diabetes," said Adia Aponte Marrero, communication and health education services coordinator. "In Puerto Rico, where diabetes is a leading cause of chronic kidney disease, our mission is vital. Motivated by the urgent need for awareness and prevention, we applied for the KHC grant to deliver culturally relevant kidney health education to high-risk populations. With the support of the American Kidney Fund, we have strengthened our outreach, built community capacity, and ensured that more people have access to the tools they need to protect their kidney health and improve their quality of life."

Community Engagement and Consultation Group Inc.

Beltsville, Maryland

"Community Engagement & Consultation Group Inc. is a community-centered initiative focused on raising awareness, promoting prevention and encouraging early management of chronic kidney disease in diverse populations," said Dr. Anita Mwalui, the founder and CEO of the organization. "Our motivation for applying for the KHC grant comes from the urgent need to build capacity within Limited English Proficiency communities to address kidney disease at its root. With this grant, we can expand culturally tailored kidney health education programs in underserved neighborhoods, leveraging the organization's capabilities in seven different languages. We also can develop sustainable pathways for ongoing kidney health promotion in collaboration with community partners and create a trusted support system for individuals at risk of CKD, caregivers and those managing its progression."

Greenville Alumni Chapter of Kappa Alpha Psi Fraternity, Incorporated Greenville, South Carolina

"One of our objectives is 'to inspire service in the public interest," said Antonio Martez, director of community relations and vice chairman of health and wellness for the fraternity. "As an organization that highlights health and wellness, when the opportunity arose to become a kidney coach and to educate the community we serve, it was a no-brainer. With the assistance and support of AKF, we had access to resources to help amplify our efforts and aid us in reaching a broader audience. Several of our chapter brothers became certified [as coaches] and shared the message with their network as well."

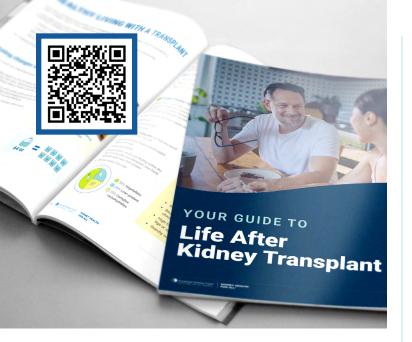
New Life Community Alliance South Dekalb, Georgia

"New Life Community Alliance's Health Services Program is a cornerstone of our holistic approach to community care," said Brandi Whitney, health program services coordinator for NLCA. "For over four years, we've led community-facing kidney health initiatives—from educational forums and monthly virtual support groups to on-site CKD screening, because we believe that prevention and early intervention save lives. We applied for the Kidney Health Coach grant to strengthen our outreach and equip trusted community members with the tools to educate and empower others. Being an American Kidney Fund grantee has amplified our impact, allowing us to expand our reach and deepen our work through the kidney coaches. Together, we're building healthier futures, one conversation and one community at a time."

Applications for our fourth cycle of the KHC Health Equity Grant program open on Jan. 9. Visit kidneyfund.org/khfa-action for more information.

For more information on the Kidney Health Coach program, visit **kidneyfund.org/khc**.





Your guide to life after a kidney transplant

KF believes that everyone who needs a kidney transplant deserves equal access to one.
Unfortunately, many people don't receive enough

information about preparing for and taking care of a new kidney following a transplant. As a result, AKF developed a guide this year for people considering a kidney transplant that gives clear, accurate information on how to prepare for life after a transplant. This guide is a follow-up to AKF's "Your Guide to Kidney Transplant" tool, which gives practical information on kidney transplants.

While a kidney transplant is considered the best treatment option for kidney failure, life after a transplant comes with questions and challenges. "Your guide to life after a kidney transplant" will help you learn what to expect following transplant surgery, covering topics such as:

- Healing from surgery
- Appointments and tests
- New medicines
- Health issues that can happen after a transplant, such as delayed graft function and side effects from medicines

Visit <u>kidneyfund.org/life-after-transplant-guide</u> or scan the QR code to view the full guide.



kidney SAVE THE DATE action Week®

March 2-5 | 2026

Mark your calendars!

The American Kidney Fund (AKF) will host its seventh annual Kidney Action Week, March 2-5, 2026.

Join us for a week of free virtual sessions about dialysis, kidney disease prevention, kidney-friendly eating, and transplant. Attend live sessions and connect with experts and health resources to help you live your best life.

Registration is coming soon!



Sign up for event details and reminders.

Thank you to our corporate members for their support in 2025

Champion





Patron















Advocates and Friends

































**





*











**



This season, we celebrate the hope and resilience of the kidney community, and the generous support of people like you who help us make a meaningful difference and help advance our mission.









How to recertify for AKF's Health Insurance Premium Program (HIPP)

KF's Health Insurance Premium Program provides vital assistance to thousands of people with kidney failure on low incomes, helping them afford their monthly insurance premiums. Each year, recipients must go through a recertification process.

Here's what you need to know:

When recertification happens

AKF reviews eligibility annually or more often, as needed. You must meet the current HIPP eligibility criteria at the time of review. These criteria can be found at kidneyfund.org/hipp.

How to recertify

Recertification must be completed through AKF's GMS (Grant Management System). It can be done by a renal professional, caregiver or the patient.

Deadline to recertify

Patient profiles must be recertified once every year, by the profile anniversary date. This date can be found in the patient's GMS record.

Why it matters

The updated information determines whether you qualify for assistance in the new coverage period.

How to contact Patient Support:

Please do not send messages, voicemails, or emails to other departments to request a call back; instead, use the communication methods listed below:

By phone: Call us at (800) 795-3226 Monday—Thursday from 11 a.m. to 2:30 p.m ET to speak with a live representative.

GMS Assist: Visit <u>GMSassist.com</u> to schedule a phone appointment for a day and time that is convenient for you. All times available are in E.T.

Through GMS: Message us through your GMS account at **gms.KidneyFund.org**. Be sure to also check the "Information" and "FAQ" tabs for more updated information.

Online: Visit KidneyFund.org to learn more about AKF's financial assistance programs, or email us at **registration@kidneyfund.org** if you are having issues registering on GMS.

Kidney failure impacts loved ones too: Ensuring caregivers take care of themselves

As someone living with kidney disease, your loved ones and caregivers play an important role in your health care team. They can help you manage your treatments, cook meals or run errands for you and help you maintain your emotional wellbeing. However, it is important that caregivers also take time for themselves. Consider sharing these tips with your caregiver to help ensure they recharge their batteries:

- Take breaks. Encourage your caregiver to schedule time on the calendar each week to focus on their own needs and do activities they enjoy.
- Accept help and ask for help when needed. Remind your caregiver that getting help can lighten their workload and allow them to take those much-needed breaks. They can make a list of tasks they need help with and then ask others for support.
- Take care of their health. Caregivers can be so focused on their loved ones' health that they forget to take care of themselves. Encourage your caregiver to get enough sleep, eat healthy meals and snacks, be active for at least 15 minutes a day, go to their yearly wellness check-up and see a therapist or counselor if they need emotional support.
- Connect with others. Talk to your caregiver about connecting with other caregivers who are going through similar experiences. This can remind them that they are not alone.

For more tips and information on caregiver self-care, visit **kidneyfund.org/caregiver-tips**.







Real people, real success stories with Velphoro

Listen to patients share their personal journeys with Velphoro.

"I would recommend Velphoro because you can break it, crush it, chew it, and it tastes great."

-Anita





"Velphoro helps me control my phosphorus and maintain it."

-Easter

"I could take one phosphate binder instead of six with each meal."

-Antonio





"Ever since we switched my phosphate binder, my phosphorus has been spot on."

-Robert

The paid testimonials provided are representative of that individual's experience, and not all patients may experience these benefits.



Watch their stories at VelphoroVoices.com.

Scan the code with your cell phone camera

INDICATION

Velphoro® (sucroferric oxyhydroxide) is a phosphate binder indicated for the control of serum phosphorus levels in adult and pediatric patients 9 years of age and older 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 buildup 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 stool, diarrhea, and nausea. Tell your healthcare provider if you have any side effect that bothers you or that does not go away.
- Discolored (black) stool is considered normal if you are taking an oral medication that contains iron, like Velphoro. Discolored stool may mask gastrointestinal bleeding, which was not a side effect of Velphoro in clinical studies.
- Before taking Velphoro, tell your doctor if you are pregnant, plan to become pregnant, or are breastfeeding.

Velphoro is available by prescription only. For additional Safety Information, please see full Prescribing Information at **Velphoro.com**. To report SUSPECTED ADVERSE REACTIONS, contact Fresenius Medical Care Customer Service at 1-800-323-5188 or FDA at 1-800-FDA-1088 or **www.fda.gov/medwatch**.



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 and pediatric patients 9 years of age and older with chronic kidney disease on dialysis.

How should Velphoro be taken?

Chew or crush Velphoro tablets, do not swallow whole.

The recommended starting dose for adults and pediatric patients 12 years of age and older is one 500 mg tablet three times daily with meals.

The recommended starting dose for pediatric patients 9 to <12 years of age is one 500 mg tablet two 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 stool (12%) and diarrhea (6%).

Discolored (black) stool is considered normal if you are taking an oral medication that contains iron, like Velphoro. Discolored stool may mask gastrointestinal bleeding, which was not a side effect of Velphoro in clinical studies.

The following adverse reactions were identified after Velphoro 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 © 2024 Fresenius Medical Care North America. All Rights Reserved.



AKF staff spotlight



Name: Sandy Tiberino

Hometown: Taipei, Taiwan

What do you do at AKF?

I am the director of accounting. My day-to-day accounting operations include reviewing invoices, monitoring payments and reviewing AKF bank activities. I also work on month-end and year-end closings,

preparing draft financial statements, our annual audit, states' registration license renewals, resolving issues and responding to internal and external inquiries related to the finance department.

Why are you passionate about fighting kidney disease?

When I first joined AKF, I did not know about kidney disease, how devastating it can be and how many people are affected. Over the years, I've learned how critical our work is and how much impact it has on patients' lives.

What is the best part of your job?

I take pride in resolving issues that come across my desk to help AKF serve the kidney community even better.

What are your favorite hobbies outside of work?

I enjoy playing volleyball, going shopping and staying active in my community. I also love traveling to different countries and within the United States to experience and learn about diverse cultures.

Kidney Kitchen®

This and other recipes can be found at kitchen.kidneyfund.org.



Gingerbread Cake

Makes: 9 servings Serving size: 1 piece



Prep time: 25 min Cook Time: 35 min

Recipe contributed by Linda Blaylock of CKD Culinary Consulting, Chef, Certified Nutritionist, Kidney Health Coach®, and Creator of the How to Eat for CKD Method.

Ingredients:

¼ cup sorghum flour

2/3 cup almond flour

1 teaspoon of baking powder

2 tablespoons unsalted butter

2 teaspoons ground ginger

1 teaspoon ground cinnamon

¼ teaspoon ground allspice

¼ teaspoon kosher salt

1/8 teaspoon ground cloves

2 teaspoons molasses

2 tablespoons of heavy cream

¼ cup cream cheese (or mascarpone), room temperature

¼ cup water

4 large eggs

½ cup (85 grams) Swerve® brown sweetener 2 tablespoons Splenda® brown sugar blend (or more Swerve® brown)

½ teaspoon baking soda

Ingredients for frosting

2 tablespoons heavy cream

 $\mbox{1}$ cup cream cheese (or mascarpone), room temperature

2 tablespoons Swerve® powdered sweetener or regular powdered sugar

½ teaspoon fresh orange zest

Nutrition Facts

(1 serving = 1 piece)

Calories = 225 Carbohydrates = 16 g Sugar = 1 g Fiber = 1 g Calcium = 107 mg Fat = 18 g Saturated Fat = 7 g Trans Fat = 0 g Protein = 6 g Phosphorus = 145 mg Cholesterol = 116 mg Sodium = 229 mg Potassium = 161 mg

Directions:

- 1. Preheat the oven to 325°F.
- 2. Line an 8×8 or 9×9 pan with parchment paper.
- 3. In a large bowl, sift together the sorghum flour, almond flour, and baking powder.
- In another bowl, melt the butter and stir in the ginger, cinnamon, allspice, salt, cloves, and molasses
- 5. Using an electric mixer or whisk, combine the heavy cream, cream cheese, water, eggs, and both brown sweeteners into the butter mixture. Batter will be lumpy.
- 6. Add the dry ingredients to the wet ingredients and mix until well combined.
- 7. When oven reaches 325°F, whisk the baking soda into the batter.
- Pour into the pan and bake, middle rack, for 30 to 40 minutes or until the top looks slightly
 moist but a toothpick comes out clean from the center.
- 9. Allow to cool for 20 to 30 minutes before frosting and cutting.

Instructions for frosting and assembly:

- 1. Whisk together the heavy cream, cream cheese, powdered sweetener, and orange zest.
- 2. Frost cake when it is cooled.
- 3. Cut into 9 pieces and serve.

Cooking Tip



Sweeteners can cause cooling aftereffects. To reduce or avoid this in the frosting, use half Swerve® powdered and half real powdered sugar, or use real powdered sugar. Using half = 17 carbs, using real only = 18 carbs.

Disclaimer: The use of sugar substitutes as a replacement for sugar is a personal choice. While sugar substitutes may offer certain benefits, such as a lower calorie count and improved blood sugar control for people with diabetes, further research is needed to fully understand the long-term health effects of these products, especially for people with chronic kidney disease. It is important to discuss any changes to what you eat and drink, including the use of sugar substitutes, with your doctor or dietitian. The information provided here is not intended to replace professional medical advice, diagnosis, or treatment.



11921 Rockville Pike Suite 300 Rockville, MD 20852 800.638.8299

KidneyFund.org

AKF is fighting on all fronts as the nation's leading kidney nonprofit. Sign-up to receive our monthly e-newsletter to get the latest updates at KidneyFund.org/sign-up.



- Fighting on all fronts in 2025
- AKF's 'Dialysis at Home' helps kidney community members make informed decisions about options
- AKF's third round of Kidney
 Health Coach Health Equity
 Grant awardees are empowering
 community members to take
 charge of their kidney health
- A guide to life after a kidney transplant
- Recertifying for AKF's Health Insurance Premium Program (HIPP)
- Kidney failure impacts loved ones too: Ensuring caregivers take care of themselves
- Staff Spotlight
- Kidney Kitchen® recipe