



SPRING 2025 | VOL. 10.1

Fighting kidney disease and helping people live healthier lives.

Kidney Month 2025: Shining a spotlight on kidney disease

Kidney-friendly eating on a budget **Connect with us**

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Mark your calendars for the second annual AMKD Awareness Day on April 29 and be 'APOL1 Aware'

On April 29, AKF is encouraging everyone to spread the word about APOL1-Mediated Kidney Disease (AMKD) Awareness Day, which aims to increase understanding and recognition of AMKD.

While everyone has two APOL1 genes, people of certain African descent are more likely to have APOL1 gene variants (mutations). If you're Black, African American, Afro-Caribbean or Latina/Latino and you inherited certain variations of the APOL1 gene, there is a greater chance of having APOL1-mediated kidney disease (AMKD). This type of kidney disease can develop even at a young age, and it can advance faster than other kidney diseases.

In becoming "APOL1 Aware," you are joining efforts to raise awareness of this genetic kidney disease. Stay tuned for posts you can share from AKF's social media channels, and check AKF's website for more resources, ways to engage and raise awareness of how your genes impact your kidney health.





For more information on AMKD Day, visit KidneyFund.org/APOL1Aware.

Leadership support for AMKD Awareness Day is provided by Vertex Pharmaceuticals, Inc. Additional support is provided by Natera.





AKF provides critical aid to patients impacted by California wildfires

Earlier this year, AKF activated its Disaster Relief Program to assist dialysis and post-transplant patients living in areas impacted by the wildfires in southern California. AKF's Disaster Relief Program is the nation's only rapid-response system that provides emergency financial assistance to dialysis and recent transplant patients, who are particularly vulnerable and prone to hardship during a natural disaster.

In the aftermath of the wildfires, emergency grants of \$250 were made available for dialysis and post-transplant patients living in the affected counties, and a total of \$6,750 in grants was provided to 27 patients in Los Angeles and Riverside County. These grants help patients replace lost medications and kidney-friendly foods, pay for temporary housing and transportation to treatment, and replenish clothing and personal essentials that have been lost due to the natural disaster or the need to evacuate with little to no notice.

AKF is grateful for the generous support of Akebia Therapeutics, Apellis, Otsuka America Pharmaceutical, Inc. and Travere Therapeutics, who provided critical aid to AKF's Disaster Relief Program efforts in Southern California.



Here are some helpful hints for patients receiving grant assistance from AKF. From recertification to post-transplant, read about the steps and forms needed to apply and manage your grants.

Recertification

AKF requires that you "recertify" that you are still financially eligible for assistance from AKF by your anniversary date. You must update your profile information, including financial details, and provide current documentation in your Grant Management System (GMS) profile annually. You also need to sign new consent forms to finalize the process.

Consent forms

Effective Jan. 1, 2025, all consent forms uploaded to the profile on or after this date must be specific to each patient and downloaded directly from their GMS profile. Patients who have claimed their account and have access to their profile can sign the new consent form electronically.

Instructions for this process can be found in the learning center once you access your profile.

Safety Net

The Safety Net Program provides grants to help people with health care expenses that are not covered by insurance, including transportation to dialysis, over-the-counter medicines, copays and other needs. On Jan. 1, 2025, AKF began accepting applications for the year.

All requests will be reviewed in the order in which they are received. While we strive to process grant requests within five days of submission, please note that processing may be limited by the program's available budget.



Steps for post-transplant HIPP extended assistance

- Claim your account: Visit gms.kidneyfund.org to claim your patient account.
- Update your profile: Add your transplant date in the "Health Information" section.
- 3. Update facility and contacts:
 - Ensure your transplant center is registered in GMS.
 If not, you can manage your account as a patient.
 - Download the Treatment Center Verification Form from your profile, complete it and return it to registration@kidneyfund.org for updates.
- 4. Check grant requests and payments: Review existing grant requests and ensure all payment information is correct. If no payments are listed, submit a new grant request following the "How to Confirm a Payment" guide in the "Information" tab.
- **5. Submit a grant request:** For HIPP extended assistance, include a bill that is no older than 90 days.

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:

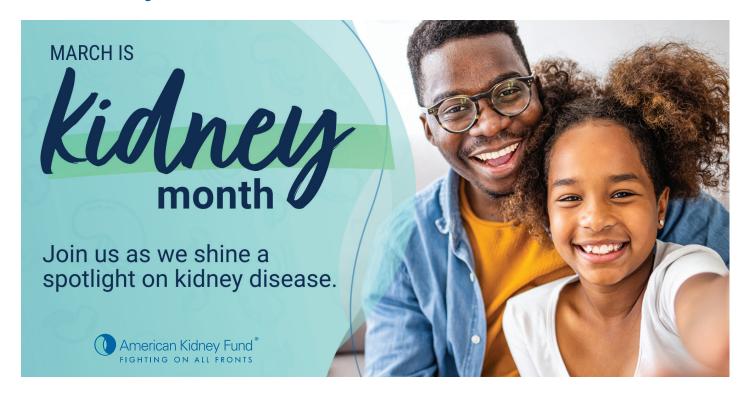
By phone: Call us at **(800) 795-3226** Monday – Thursday from 11 a.m. to 2:30 p.m. ET to speak with a live representative.

GMS Assist: Visit **GMSassist.com** to schedule a phone appointment for a day and time that is convenient for you. All times available are in ET.

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 <u>KidneyFund.org</u> to learn more about AKF's financial assistance programs, or email us at <u>registration@kidneyfund.org</u> if you are having issues registering on GMS.

Kidney Month 2025: Shining a spotlight on kidney disease



On March 1, AKF kicked off Kidney Month to shine a spotlight on kidney health and kidney disease. The goal of Kidney Month is to elevate the voices of the kidney community, including AKF Ambassadors, caregivers, health professionals and supporters, as well as empower those at risk of developing kidney disease to prevent it and help people living with the condition live longer, healthier lives.

We hope you were able to join us for our sixth annual Kidney Action Week® (KAW) March 3-7. Each day of KAW featured empowering educational sessions designed to give people the knowledge and tools they need to take charge of their kidney health, covering topics such as rare kidney disease, kidney disease prevention and management, dialysis, transplant and organ donation and clinical research. If you weren't able to attend KAW, visit youtube.com/@kidneyfund/playlists to watch replays of the KAW sessions.

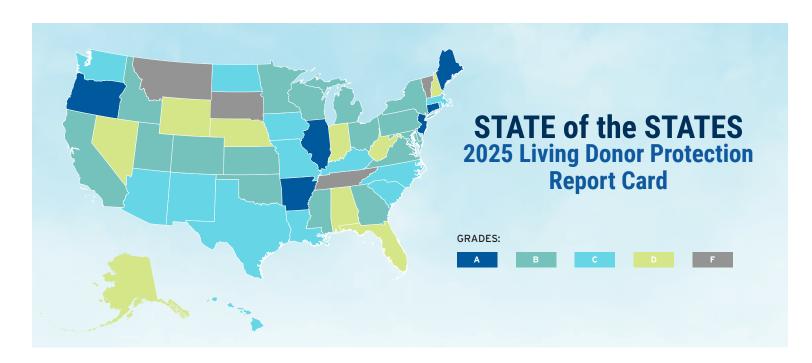
Kidney Month highlighted a variety of kidney-related topics, including rare kidney diseases and transplantation. Kidney Month provided an opportunity to share new videos featuring members of AKF's Rare Kidney Disease Action Network (RKDAN). Visit **kidneyfund.org/rkdaninfo** for more information on RKDAN, and **kidneyfund.org/akftransplantpage** to explore AKF's transplant webpage.

On March 13, we observed World Kidney Day to raise awareness of the importance of our kidneys to overall health. AKF shined a spotlight on our Know Your Kidneys® initiative, which provides people at risk for kidney disease and those living with kidney disease with comprehensive, interactive resources to support them through the entire kidney disease journey. To learn more about Know Your Kidneys, visit kidneyfund.org/know-your-kidneys. Information on World Kidney Day can be found at bit.ly/WorldKidneyDay2025.

AKF also shined a spotlight on our Kidney Health for All™ campaign, along with our Kidney Health Coach Program, a free, community health education program that equips health professionals and the public with the knowledge and tools they need to educate patients and community members about preventing and managing kidney disease. Visit kidneyfund.org/kidney-health-for-all and kidneyfund.org/kidneyhealthcoach for more information.

To learn more about Kidney Month, visit AKF's Kidney Month hub at KidneyFund.org/kidney-month.

AKF is grateful to Amgen, Boehringer Ingelheim and Lilly and Company, Travere Therapeutics and Vertex Pharmaceuticals, Inc. for their support of AKF's Kidney Month activities.



AKF releases new Living Donor Protection Report Card, looks ahead to advocacy priorities for 2025

Since 2021, the American Kidney Fund has graded each of the 50 states and the District of Columbia on how well their laws encourage living organ donation and reduce barriers for living donors.

Our fifth annual Living Donor Protection Report Card shares progress made in 2024: Michigan, Mississippi, New Hampshire and South Carolina all passed new laws that provide protection or financial support for living organ donors, bringing the total number of states that have enacted living donor protections since the launch of the report card to 24. However, there is more work to do, as only six states have an A grade – meaning they have enacted at least 5 of the 7 types of legislation or regulations that can encourage living donation. For more information about how the states are graded, visit livingdonor.kidneyfund.org/grading/.

In 2025, AKF will continue to work with our nationwide Ambassador network to urge states to pass more laws that will encourage and support people to become living donors. Meanwhile, on the federal side, we are calling on the new Congress to reintroduce the Living Donor Protection Act in both the U.S. House of Representatives and Senate. This federal legislation would provide baseline protections nationwide, ensuring that living organ donors have Family and Medical Leave Act (FMLA) and anti-discrimination protections. Passage of this legislation would mean that the lowest Report Card grade any state could receive would be a C.

AKF's advocacy efforts will also focus on the following in 2025:

- Improving early detection and upstream care of kidney disease
- Addressing the unknown causes of kidney disease, including rare kidney diseases
- Encouraging organ donation and supporting kidney transplants
- Ensuring access to high quality, patient-centered care for Medicare beneficiaries with kidney disease
- Protecting access to health coverage under the Affordable Care Act, Medicaid and employer-sponsored insurance
- Addressing health disparities that impact people with kidney disease

For more information on how to get involved with AKF's advocacy efforts, visit **kidneyfund.org/get-involved**.

Visit AKF's Living Donor Protection Report Card webpage at **livingdonor.kidneyfund.org**.

AKF's local programs supporting living kidney donors combine to form new Living Donor Assistance Program

This winter, AKF announced the consolidation of two vital initiatives – the David Atkins Fund and the living donor assistance program in the Washington, D.C. metropolitan area – that aim to remove financial barriers to living donation. Now known as AKF's Living Donor Assistance Program, this effort will continue to provide financial assistance to living kidney donors anywhere in the country who are donating a kidney to a recipient in Massachusetts, the Washington, D.C. metropolitan area and New York City.

The combined program hopes to expand to other geographic areas as it receives additional funding.

Grant specifics

- Grants are for reimbursement of out-of-pocket travel-related and childcare expenses incurred by living donors
- Grants are up to \$2,500 per donor
- One lifetime grant is available per living kidney donor

Eligibility

Open to individuals who donated a kidney within the
 12 months prior to their application submission date

- Kidney recipient's evaluation and/or surgery took place at a hospital in Maryland, District of Columbia, Northern Virginia, New York City or Massachusetts
- Donor incurred out-of-pocket expenses not covered by insurance or reimbursed by a similar assistance program
- Donor must permanently reside in the U.S. or its territories
- Living donor or recipient financial information is not required or considered when evaluating applicants for program eligibility

To apply

For more program specifics or to apply, visit the individual grant application page for the kidney transplant recipient's location:

- Massachusetts kidneyfund.org/manylivingdonorfund
- New York City kidneyfund.org/manylivingdonorfund
- Washington, D.C. Metro Area
 kidneyfund.org/dclivingdonorfund

For questions regarding the Living Donor Assistance Program, please reach out to livingdonor@kidneyfund.org.

To view the Living Donor Assistance Program webpage, visit **kidneyfund.org/ldap**.

The Living Donor Assistance Program is made possible in part by support from the Sievers Family Charitable Fund and the Friends of David Atkins.





Kidney-friendly eating on a budget

Following a kidney-friendly eating plan is essential for people with kidney disease. However, it is not always easy if you are on a tight budget. Whether you live far from a grocery store or struggle to afford fresh, healthy foods because you are juggling medical costs and other expenses, AKF has practical tips and resources for stretching your food budget.

Shop smart for groceries

When grocery shopping, consider these tips to make shopping easier:

- Make a list and stick to it
- Compare prices and brands
- Buy in bulk when practical
- Look for sales and use coupons
- Request specific items from local stores
- Shop online when it makes sense to do so
- Shop seasonal and local produce

To download our guide for a list of items to keep stocked in your home, visit **kidneyfund.org/akfgrocerylist**.

Limit eating out

If you are eating out, consider these cost-saving ideas:

 Order your food to go and pick it up at the restaurant to avoid delivery charges.

- Order a healthy appetizer or two instead of a big main course.
- Share your meal with a friend and split the cost.
- Save leftovers in a to-go container to enjoy later.

Restaurant food is often high in sodium and filled with preservatives. You can protect your kidneys by planning ahead with these tips for dining at fast-casual or fast-food restaurants: kidneyfund.org/fastcasualfoodtips. You can also find tips on dining out with confidence here: kidneyfund.org/diningoutfoodtips.

Use a food pantry wisely

Food pantries provide a variety of budget-friendly foods. Unfortunately, many of these foods are high in phosphorus, sodium and other additives that preserve their shelf life but can harm kidneys. Read the food labels and ingredients to ensure you choose kidney-friendly options. Here are some tips on what foods to choose and what to limit when you're stocking up at a food pantry:

- Canned goods: Choose unsweetened canned fruits or canned fruits in 100% juice. Limit canned chili, stews, soups; baked or refried beans; fruit in juice or syrup; premade sauces and dressings.
- Grains: Choose whole grain options like brown rice, quinoa, pasta and cereal. Limit boxed macaroni and cheese and instant noodles.
- Packaged snacks: Choose whole grain crackers, air-popped popcorn, unsalted nuts or seeds and dry fruits without added sugar. Limit chips, crackers and cookies.
- Dairy: Choose low-fat or fat-free dairy milk or yogurt, lactose-free dairy or fortified soy products. Limit processed cheeses.
- Protein: Choose fresh or frozen lean meats, poultry, fish, beans and peanut butter without added sugar.
 Limit processed meats like deli meats, hot dogs, sausage and pepperoni.
- Vegetables: Choose fresh, frozen or low-sodium canned vegetables. Limit potatoes, especially fried or in processed forms like chips or hash browns.

For more budgeting tips and for a list of food resources near you, visit **kitchen.kidneyfund.org/eating-on-a-budget/**.







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).

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AKF staff spotlight



Name: John O'Brien

Hometown: Washington, D.C.

What do you do at AKF? I am the director of individual giving. I am responsible for developing and executing strategies to secure financial contributions from individual donors, including major gift prospects, by identifying and cultivating relationships and soliciting meaningful commitments to support the mission of AKF.

What is your personal connection to kidney disease?

I have several family members with kidney disease, including my father, who is living with stage 3 kidney disease.

Why are you passionate about fighting kidney disease?

Intuitively, I like the idea of helping people in general. I've learned so much about the importance of kidney health, prevention and education. It's so important to educate at-risk communities on the risks of CKD. I've seen how diseases like kidney disease, diabetes and high blood pressure are accepted as a normal occurrence as you age. Changing that narrative is extremely important, and supporting patients who crash into the life-changing reality of kidney disease is important to me.

What is the best part of your job? The best part of my job is the relationships that I've been able to build over the years with passionate individuals who want to make a difference. Helping them realize their capacity to make the biggest impact toward a cause they feel passionate about is a win-win! It's a win for them and a win for those who depend on AKF for support.

What are your favorite hobbies outside of work?

My hobbies include exercising, attending Washington Commanders home games and hanging out at Barnes and Noble with Starbucks.

Kidney Kitchen®



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



Creamy Chicken Mac

Makes: 4 servings Serving size: 3/4 cup



Prep time: 10 min Cook time: 15 min

Recipe contributed by Satellite Healthcare

Nutrition facts

 $(1 \text{ serving} = \frac{3}{4} \text{ cup})$

Calories = 426 Carbohydrates = 72 g Sugar = 3 g Fiber = 4 g Calcium = 39 mg Fat = 8 g Saturated Fat = 2 g Trans Fat = 0 g Protein = 20 g Phosphorus = 80 mg Cholesterol = 29 mg Sodium = 225 mg Potassium = 306 mg

Ingredients:

2 tablespoons margarine

2 tablespoons flour

1/4 cube low-sodium chicken bouillon

1 ½ cups water

2 tablespoons cream cheese

1 tablespoon mayonnaise

½ teaspoon onion powder

14 teaspoon garlic powder

¼ teaspoon ground black pepper

14 teaspoon salt

4-ounce chicken breast, cubed and cooked

3 cups elbow macaroni, cooked to package instructions

1 teaspoon lemon juice (optional)

Directions:

- Add margarine and flour to a skillet on medium heat, cook a few minutes, whisking to prevent lumps from forming.
- In a separate bowl, dissolve bouillon in water. Add to skillet slowly, whisking as it thickens.
- 3. Melt in cream cheese and mayonnaise.
- 4. Add onion and garlic powders, pepper and salt, continuing to stir.
- Add cooked chicken and macaroni, stir to coat.
- 6. Add lemon juice at the end (if desired).



Cooking Tip:

Add in some greens such as peas or cooked broccoli



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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.

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