

Fighting kidney disease and helping people live healthier lives.

Heroes and Changemakers honored at The Hope Affair

AKF's new podcast 'The Kidney
Collective' gives a voice to
members of the kidney community

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# Working with your doctor to find the cause of your kidney disease

hen you are living with kidney disease, knowing what caused it helps you and your doctor make the best possible treatment plan and use targeted therapies. Even if you are on dialysis, knowing the cause of your kidney disease can help you decide steps to take to protect a kidney transplant, know if you qualify for a clinical trial and protect your overall health and the health of your loved ones. The first step to finding the cause of your kidney disease is to work with your doctor. Here are some tips to help you get the most out of your next visit:

# Preparing for your appointment

- Write down your symptoms and how you have been feeling overall. Include as much detail as you can.
- Bring a list of any medicines you take, including herbal supplements and over-the-counter medicines (such as pain relievers).
   You can also bring your medicines with you.
- Write down your questions and put your three most important questions at the top. Our Know Your Cause tool can help

prepare customized questions for you. Visit <u>kidneyfund.org/</u> <u>know-your-kidneys/cause</u>.

 Ask a friend or family member to come with you for support and to help you remember information.

#### **During your visit**

- Go over your list of symptoms with your doctor and tell them about any changes to your health. Give as much detail as you can, even if it does not seem related to your kidney disease—anything may help in finding the cause.
- Ask your most important questions first. Start with the two to three questions at the top of your list to make sure there is time to answer them.
- Take notes so you can look up information later. If you don't understand, ask the doctor to explain in a different way.
- Ask for resources to learn more.
   Your doctor may have brochures, fact sheets or links to trusted online sources where you can do more research.
- Ask what the next steps are.
   Before the end of your visit, make sure you know what you need to

do next, including labs, follow-up, referrals or medicines. For many people, it can take awhile for your health care team to find the reason behind your kidney disease. In some cases, it actually may not be possible to figure out, but don't give up hope. Our understanding of how our genes and other factors play a role in kidney disease is improving quickly. No answer today does not mean there will be no answer tomorrow.

# Tips to make sure you understand all the information

You may get a lot of new information, and your doctor may use words or talk about concepts that are new to you. You can:

- Ask follow-up questions and/ or ask your doctor to repeat information if anything is unclear.
- Repeat information back to your doctor in your own words.

For more information about working with your doctor, including when and how to get a second opinion, visit **kidneyfund.org/uckd-cause** or use the QR code below.

Scan the QR code:



# Heroes and Changemakers honored at The Hope Affair

n October, AKF will hold its 17th annual gala, The Hope Affair®, which brings together members of the kidney community—patients, advocates, caregivers, health professionals and innovators—and honors AKF's 2025 Hero of Hope and Changemakers Award recipients:



## Hero of Hope: Tamara Y. Walker

Educator, advocate, mentor, volunteer and mother of two adult sons, Tamara Y. Walker is a kidney warrior. She was diagnosed with autosomal dominant polycystic kidney disease

(ADPKD) in 2000. After two years of dialysis, a diagnosis of kidney cancer, removal of both kidneys, and a kidney transplant in 2024, Tamara decided to give back and become an AKF Ambassador and a Kidney Health Coach® to raise awareness of ADPKD and kidney disease. She continues to engage and assist in community outreach by working at events, sharing her story and facilitating online educational sessions about kidney disease.



# Changemakers: Matt and Julia Glazier and David Atkins

Two years ago, in partnership

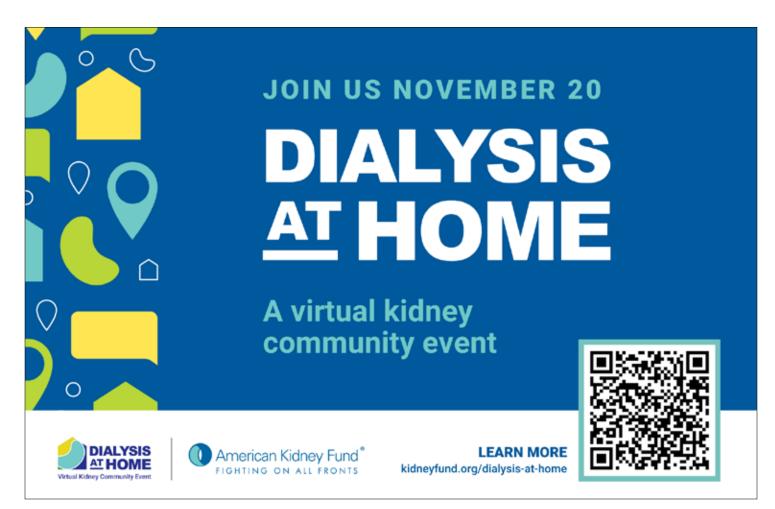
with AKF, living donor champions Matt and Julia Glazier launched the David Atkins Fund, now known as the Living Donor Assistance Program™. The fund was named after Matt and Julia's good friend David Atkins, who stepped up as a living donor and gave Matt one of his kidneys after he was diagnosed with atypical hemolytic uremic syndrome (aHUS) and was in need of a kidney transplant.

The program distributes grants to living donors to help pay for expenses that are not covered by insurance, such as childcare, travel expenses and lost wages.

For more information on the Living Donor Assistance Program, visit **kidneyfund.org/ldap** or use the QR code to the right.

Scan this QR code:





# Living donors reflect on how AKF's Living Donor Assistance Program supported them

KF's Living Donor Assistance Program™ seeks to increase access to living kidney donations by reimbursing out-of-pocket costs for current and potential living kidney donors, easing the financial burden that is associated with giving the gift of life. Here are snapshots of two of those donors:



#### **Carmen Figueroa**

In January 2025, Carmen donated one of her kidneys to her brother, who has focal segmental glomerulosclerosis (FSGS), a serious and rare kidney disease. Although Carmen was able to take time off work to

donate without fear of losing her job, she faced costs that were not insignificant, including two sets of cross-country flights between California and Massachusetts.

"[The Living Donor Assistance Program] gave me \$2,500. I did not expect that. I expected nothing, but when [the program] helped me, that was very humbling," she said. Carmen used that funding to cover the price of her flights.

Visit **kidneyfund.org/carmen** to read Carmen's full donation story.



#### Julianne O'Reilly

Julianne met Elliot—the man she donated a kidney to in 2024—while volunteering at her church. Driving back and forth to the hospital for testing and for the surgery itself involved little expenses that added up, like paying for parking or meals.

The Living Donor Assistance Program helped cover those expenses and made it possible for Julianne's husband to take some time off work to visit her in the hospital.

"It's very unknown," Julianne said when describing the donation process. "You don't know if you'll be able to feel better right away and go back to work and just being able to know that we had a bridge if we need it, it relieved a lot of anxiety."

Visit <u>kidneyfund.org/julianne</u> to read Julianne's full donation story.

If you are on the transplant waiting list at a center in Massachusetts, New York City, Illinois, Maryland, Virginia or the District of Columbia, financial assistance through the Living Donor Assistance Program may be available to your donor. In the Washington, D.C. metropolitan area, grants are also available to those going through testing prior to transplant. Living kidney donors can reside anywhere in the country. Learn more at kidneyfund.org/ldap.

# Changes to Medicaid, ACA Marketplace and SNAP signed into law: What kidney patients should know about the budget reconciliation bill

n June, the President signed H.R. 1 into law, also known as the One Big Beautiful Bill Act. This law includes significant funding cuts to many important programs for kidney patients: \$990 billion to Medicaid, \$213 billion to federal Affordable Care Act (ACA) marketplaces and \$280 billion in Supplemental Nutrition Assistance Programs (SNAP) over 10 years. The nonpartisan Congressional Budget Office has estimated that by 2034, H.R. 1 will result in 10 million people becoming uninsured. The cuts to Medicaid and SNAP are the largest ever cuts to the nation's safety net.

The impact of H.R. 1 on people living with kidney disease will be considerable given that Medicaid is a vital part of the nation's safety net for people with low incomes and millions of people living with kidney disease rely on Medicaid for their health care. Losing health coverage means people will lose access to health care providers, services and treatments that can help manage CKD and any comorbidities.

To get the details on the Medicaid, ACA and SNAP provisions in the new law and how they could impact you, visit **kidneyfund.org/hr-1**.



## When disaster strikes, **AKF** works with **Kidney Community Emergency Response** (KCER) and End Stage **Renal Disease (ESRD) Network Program**

or people receiving dialysis or living with a kidney I transplant, planning for emergencies and disasters can be the difference between life and death. Dialysis and transplant patients must take special preparedness measures to ensure their own health and safety during and after disasters.

Luckily, when a disaster strikes, there is support available from AKF's Disaster Relief Grant Program, a rapid-response system that provides emergency financial assistance to people affected by a natural disaster who are living with kidney failure. Recently, AKF activated this program in central Texas to assist dialysis and post-transplant patients who had been impacted by the devastating floods that hit the area in July. This grant program wouldn't be possible without the help of two kidney-related organizations: The Kidney Community Emergency Response (KCER) Program and The National Forum of ESRD Networks. AKF works with these organizations to determine what level of need there is for assistance in areas impacted by a natural disaster. Here is an overview of these organizations:

#### **KCER Program**

When a disaster happens, AKF's patient support department reaches out to KCER, which serves as the leading authority on emergency preparedness and response for the kidney community. Under contract with the Centers for Medicare & Medicaid Services (CMS), KCER provides technical assistance to ESRD Networks, kidney organizations and other groups to ensure timely and efficient disaster preparedness, response and recovery for the kidney community.

The KCER program's disaster preparedness resources help save lives, improve outcomes, empower patients and families, educate health care workers, build partnerships with stakeholders, promote readiness in the community and support the ESRD Network Program in disaster coordination efforts. This support consists of providing resources, expertise and educational materials for ESRD Networks. In the event that a crisis requires assistance outside of an ESRD Network's capacity, KCER resources are available.

#### The National Forum of ESRD Networks

Under the direction of CMS, the ESRD Networks consists of a national network of 18 ESRD Networks, responsible for each U.S. state, territory and the District of Columbia. ESRD Networks serve geographic areas based on the number and concentration of ESRD beneficiaries, meaning that some networks represent one state, while others represent multiple states. The organization works with consumers, ESRD facilities and other providers of ESRD services to refine care delivery systems to make sure ESRD patients get the right care at the right time.

For more information on AKF's Disaster Relief Grant Program, visit kidneyfund.org/disaster-relief/ and kidneyfund.org/disaster-strikes.

Visit www.kcercoalition.com/en/ for more information on the Kidney Community Emergency Response program.

More information on the National Forum of ESRD Networks is available at esrdnetworks.org.

For more information on AKF's **Disaster Relief Grant Program,** scan this OR code:



# AKF releases new Kidney Health for All resources to empower people living with kidney disease

KF recently announced new resources to empower people who are living with kidney disease with the necessary information to have meaningful conversations about kidney health and make health care decisions that meet their unique needs. Developed as part of AKF's Kidney Health for All™ health equity program, these resources are available in English and Spanish:

- Empowering Choices: Your guide to making the best dialysis decisions for you: This updated version of the award-winning Home Dialysis Decision Aid tool helps you understand the dialysis options available to you (including home dialysis), the benefits and challenges of each option and how to choose the best dialysis treatment for you.
- Talk with your doctor about clinical trials: A companion to the clinical trial guide for providers, this guide includes information for patients on what clinical trials are, why you should join them, questions to ask your doctor and tips to check your understanding, as well as a section to write notes.

- Get empowered to talk to your doctor: This video featuring AKF Chief Medical Officer Dr. Pranav Garimella is designed to help patients ask important questions of their doctor, from those that are common to some that may be uncomfortable.
- Organ and tissue donation: Myths debunked: This resource helps patients learn the facts of organ and tissue donation and debunks common myths.

Visit <u>kidneyfund.org/khfa-resources</u> to explore the resources. AKF's Kidney Health for All program can be viewed at <u>kidneyhealthforall.org</u>.

AKF is grateful to the members of the Health Equity Coalition, established in 2021, which helps guide the development of evidence-based programs and resources for AKF's patient and professional audiences.

Kidney Health for All is supported by Presenting Sponsors Boehringer Ingelheim and Lilly and Company and Vertex Pharmaceuticals, Inc. and Equity Sponsors AstraZeneca, Merck and Co., Otsuka America Pharmaceutical, Inc., Sanofi and Travere Therapeutics.

## **AKF staff spotlight**



Name: Shahzia Lakhani

Hometown: Miami, Florida

#### What do you do at AKF?

I am the senior director of clinical education. I focus on providing specialized clinical expertise to support AKF staff day-to-day, drive our clinical education program and represent AKF's position on scientific

and medical issues. I also am responsible for ensuring our education materials are medically accurate and all recommendations for patient care align with updated clinical practice guidelines.

#### What is your personal connection to kidney disease?

I am a transplant nurse practitioner, practicing in the care of kidney transplant recipients, ensuring education and supporting knowledge about the transplant process.

#### Why are you passionate about fighting kidney disease?

I have seen firsthand how silently it can affect lives. I've seen the emotional and physical toll kidney disease takes—not just on patients, but on their families. Kidney disease disproportionately affects communities of color and those with limited access to care. I'm passionate about addressing those disparities—whether through education, outreach or working to advocate for policy changes that impact early diagnosis and treatment.

#### What is the best part of your job?

Learning about the new innovations in kidney disease evaluations and treatments. I stay connected to new research and therapeutics to gain knowledge about the opportunities for our kidney disease community.

#### What are your favorite hobbies outside of work?

Outside of work, I enjoy traveling and taking photos. It helps me observe things from different perspectives, which often feeds back into my work in meaningful ways.

# AKF's new podcast 'The Kidney Collective' gives a voice to members of the kidney community

n August, AKF proudly launched its first-ever podcast, "The Kidney Collective™." Introduced as a seven-episode, limited series, The Kidney Collective gives an intimate voice to the many facets of living with kidney disease.

Each episode features a conversation with a member of the kidney community and is dedicated to a topic such as slowing kidney disease, crashing into dialysis, navigating mental health challenges, pushing for an accurate diagnosis, genetic testing, home dialysis and being a living donor. Guests share their unique experiences and what they wish they knew at the start of their kidney disease journeys. Through these casual, informative and personal conversations, The Kidney Collective provides a space in

which listeners can learn from and relate to others going through the experience of living with kidney disease or kidney failure.

Episodes of The Kidney Collective are now available and published biweekly through the end of the limited series. The podcast is available wherever you listen to podcasts or on AKF's YouTube channel. Educational resources discussed in each episode will be included in the episode show notes as well as on The Kidney Collective website.

To find out more about The Kidney Collective, including host and guest bios, episode descriptions and more, visit **kidneyfund.org/podcast**.



## AKF launches kidney health innovations webpage

reatments and advanced technologies are changing what's possible for people with chronic kidney disease (CKD). On AKF's new kidney health innovations webpage, you can find information about:

- FDA-approved innovations and promising research that's in development
- New kidney medicines
- New ways to manage CKD symptoms
- Developments in kidney transplants

- New opportunities in dialysis
- Genetic testing breakthroughs
- Advancements in rare disease research
- How to join a clinical trial
- Finding out the cause of your kidney disease

Stay informed, talk to your doctor, explore what's on the horizon and do your own research to be your best advocate. Visit the page at kidneyfund.org/kidney-health-innovations.







## 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

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## **Kidney Kitchen®**

ith the start of fall comes all things pumpkin spice, whether that be a latte, a muffin or a cookie. But while pumpkin is a wonderful flavor, there are other flavors and spices traditionally associated with fall that are just as delicious and just as fun to bake and cook with. Here are some of AKF's favorite kidney-friendly fall recipes that you can make and enjoy as the weather starts to cool down:



#### **Ginger Apple Bites**

These tiny, moist muffins are a sweet, bite-sized treat you are sure to love! They only take 20 minutes to prepare and 15 minutes to bake. The ingredients you will need are: dried apples, unsweetened applesauce, unsalted butter, flour, ground ginger, ground cinnamon, vanilla, ground nutmeg, ground allspice and salt. Read the full recipe at kidneyfund.org/ginger-apple-bites.





#### **Cinnamon Molasses Cookies**

These flavor-packed cookies are low carb, low sugar and gluten free, and they take 20 minutes to prepare and 20 minutes to bake. The ingredients you'll need are coconut oil, an egg, molasses, Splenda® brown sugar blend, almond flour, gluten free oat flour, gluten free baking powder, baking soda, ground cinnamon, ground ginger, ground nutmeg, ground cloves and salt. Read the full recipe at kidneyfund.org/cinnamon-molasses-cookies.





#### **Fall Cabbage Salad**

This salad unites a coleslaw with a Waldorf-type salad through the creamy homemade dressing. It takes just 15 minutes to prepare and 15 minutes to cook and requires the following ingredients: shallot, an egg, Dijon mustard, maple syrup, apple cider vinegar, grapeseed oil, mixed cabbage, golden delicious apples, plums, red onion, hearts of palm, dill, dried cranberries, black pepper, hazelnuts and crème fraiche (this ingredient is optional). Read the full recipe at **kidneyfund.org/fall-cabbage-salad**.





#### **Apple Cider Chicken and Veggies**

This dish has a variety of textures and flavors. It contains a bit of sweetness paired with savory flavors and a burst of warming spices. It takes 30 minutes to prepare and 30 minutes to cook and requires the following ingredients: ground cinnamon, ground cumin, salt, pepper, thyme, fennel seeds, allspice, boneless and skinless chicken thighs, Worcestershire sauce, oil, yellow zucchini squash, apple cider (with no potassium added), apple cider vinegar, carrots, parsnips, salt, frozen riced cauliflower, salt-free roasted peanuts and sweet-tart apples. Read the full recipe at kidneyfund.org/apple-cider-chicken.



**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.

For more recipes from our Fall Favorites collection, visit kidneyfund.org/fall-recipes. Visit kitchen.kidneyfund.org for all recipes.



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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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