

Chris Bryant, Avenel, NJ  
AKF Ambassador

SUMMER 2024 | VOL. 9.2

# AKF in ACTION


Fighting kidney disease and helping people live healthier lives.


**2** AKF launches national kidney health equity media campaign

**3** AKF calls for more awareness and understanding of APOL1-mediated kidney disease


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## Kidney Action Summit brings AKF Ambassadors to Capitol Hill to advocate for kidney patients and living donors

**O**n May 15, more than three dozen AKF Ambassadors—kidney patients, kidney donors and caregivers—met with lawmakers on Capitol Hill in Washington, D.C., to urge support for H.R. 5027, the Chronic Kidney Disease and Improvement in Research and Treatment Act of 2023, which would increase awareness of kidney disease and expand preventative services. Ambassadors also sought congressional support for the Living Donor Protection Act of 2023 (S.1384/H.R. 2923), which would safeguard vital job protections for living organ donors and prohibit insurance companies from declining or limiting specific insurance coverage due to their status as a living organ donor.

The annual Kidney Action Summit began on May 14 with a full day of training and networking. During this training, Ambassadors learned about how Capitol Hill works and practiced telling their stories to their senators and representatives on how kidney disease has impacted their lives.

“It’s a privilege to be able to meet with members of Congress and relay specifically the issues that kidney patients have,” said Stephanie Dixon, an AKF Ambassador from New Jersey.

“It’s so important to share our personal stories with members of Congress, the individuals we’ve elected to make decisions and create laws for us,” said Tamara Walker, an AKF Ambassador from Georgia. “AKF’s Summit paves a way to make our voices heard by sharing our unique kidney journeys. By doing so, the lives of those affected by kidney disease may have a more positive outcome.”

To learn more about becoming an AKF Ambassador and getting involved in AKF’s Advocacy Network, visit [bit.ly/AKFAdvocacyNetwork](https://bit.ly/AKFAdvocacyNetwork).



## Join AKF's Rare Kidney Disease Action Network

**A**KF is looking for patients with rare and genetic kidney diseases to join our newly formed Rare Kidney Disease Action Network. As a member of the network, patients will connect with other people living with rare kidney diseases, learn more about the policy issues impacting kidney care and receive training on how to educate lawmakers and the public about kidney disease and share their kidney stories. Patients' experiences will also help inform and guide AKF's work to assist rare kidney disease patients.

You may be eligible to join the network if you have any of the following kidney diseases:

- IgA nephropathy
- Polycystic kidney disease
- APOL1-mediated kidney disease (AMKD)
- Lupus nephritis
- Alport syndrome
- Atypical hemolytic uremic syndrome (aHUS)
- Focal segmental glomerulosclerosis (FSGS)
- Primary hyperoxaluria (PH1 or PH2)
- Cystinosis
- Fabry disease
- Dent disease
- Complement 3 glomerulopathy (C3G)

*The Rare Kidney Disease Action Network is made possible with support from Otsuka America Pharmaceutical, Inc., Novartis and Traverre Therapeutics, Inc.*

Please use the QR code below or visit [kidneyfund.org/rare-disease-survey](https://kidneyfund.org/rare-disease-survey) to learn more about the Network and express your interest in joining.

To learn more about the Rare Kidney Disease Action Network, scan this QR code:



## AKF launches national kidney health equity media campaign

**K**idney disease doesn't get the attention it deserves, and AKF is working to change that. This spring, we launched a national media campaign to raise awareness and help people prevent kidney disease and avoid dialysis. This yearlong campaign is a part of AKF's Kidney Health for All™ initiative, which centers around four pillars:

- Preventing and slowing the progression of kidney disease
- Increasing diversity in clinical trials to reflect the populations the medications will treat
- Increasing awareness and utilization of home dialysis, which can result in better outcomes
- Increasing access and removing barriers to kidney transplantation among people of color

For more information on the campaign and for resources on home dialysis, clinical trials or a kidney transplant, visit [KidneyHealthForAll.org](https://KidneyHealthForAll.org).

*Kidney Health for All is supported by Presenting Sponsors Boehringer Ingelheim and Eli Lilly and Company, Traverre Therapeutics, Inc., and Vertex Pharmaceuticals Incorporated; Leadership Sponsors AstraZeneca and Merck; and Equity Sponsors Otsuka America Pharmaceutical, Inc. and Sanofi.*





## AKF calls for more awareness and understanding of APOL1-mediated kidney disease

**A**pril 30 marked the nation's first ever APOL1-mediated kidney disease (AMKD) Awareness Day, launched by AKF to increase recognition of this serious genetic disease and urge people to consider how where they come from can impact their kidney health.

AMKD is a spectrum of kidney diseases associated with variants (mutations) in the apolipoprotein L1 (APOL1) gene and linked to an increased risk for rapidly progressing kidney disease. While everyone has two copies of the APOL1 gene, people who have western and central African ancestry are at an increased risk of having a mutation in one or both genes, leaving them more susceptible to developing genetic forms of kidney disease such as focal segmental glomerulosclerosis (FSGS).

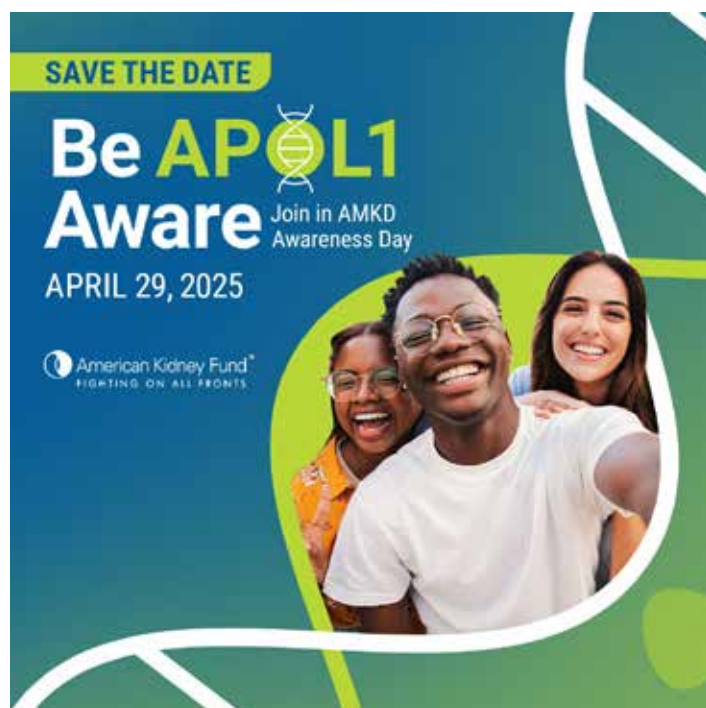
As part of this inaugural event, AKF led a panel about AMKD at the National Minority Quality Forum's (NMQF) Annual National Leadership Summit on Health Disparities, available to watch at [bit.ly/NMQFpanel](https://bit.ly/NMQFpanel). AKF also hosted a patient and policy roundtable discussion on Capitol Hill on April 9, with basketball Hall-of-Famer Alonzo Mourning

as the featured speaker. Mourning has been active in spreading the word about AMKD since being diagnosed with the condition.

Visit [KidneyFund.org/APOL1aware](https://KidneyFund.org/APOL1aware) for more information on AMKD.

To learn more about the first AMKD Awareness Day, visit [bit.ly/AMKDDayRelease](https://bit.ly/AMKDDayRelease).

*Support for AMKD Awareness Day was provided by Vertex Pharmaceuticals Incorporated.*





## AKF's new Know Your Kidneys program provides roadmap to better kidney health

This spring, AKF announced a major expansion of its award-winning Know Your Kidneys program, providing people living with kidney disease with comprehensive, interactive resources. On the program's dedicated webpage ([KidneyFund.org/Know-Your-Kidneys](https://KidneyFund.org/Know-Your-Kidneys)), visitors are directed to one of three pathways based on their current health and specific needs, two of which are: Know Your Cause and Know Your Plan.

- Know Your Cause**—This pathway (available at [kidneyfund.org/know-your-kidneys/cause](https://kidneyfund.org/know-your-kidneys/cause)) provides disease-specific content on possible causes of a person's existing kidney disease, including diabetes, hypertension (high blood pressure), or a rare or genetic disease. Know Your Cause offers information about testing options, finding a genetic counselor and participating in clinical trials, as well as an interactive tool to guide patients on how to speak with their doctor about identifying the cause of their kidney disease.
- Know Your Plan**—This pathway (available at [kidneyfund.org/know-your-plan](https://kidneyfund.org/know-your-plan)) provides information to people who know they have chronic kidney disease or kidney failure and want more guidance on living a healthy life with their condition. Know Your Plan offers guidelines on nutrition, physical activity and managing mental health, along with information about treatment options. Additionally, there is an interactive tool that enables patients to create a custom and actionable plan for managing their kidney disease.

AKF's expanded Know Your Kidneys program is made possible with the support of Boehringer Ingelheim and Eli Lilly and Company, Otsuka America Pharmaceutical, Inc., Travers Therapeutics, Inc. and Novartis.

The homepage for the expanded Know Your Kidneys program is available at [KidneyFund.org/Know-Your-Kidneys](https://KidneyFund.org/Know-Your-Kidneys), as well as through the QR code below.

To explore AKF's Know Your Kidneys program, scan this QR code.



## Reminders from AKF's Patient Support team

### Patients' profile

Keep informed about payments, grant request submissions and account status by claiming your existing profile. Claiming your account will grant you access to the account already created by your dialysis facility. For more information, visit [bit.ly/HIPPinfo](https://bit.ly/HIPPinfo), then download the AKF Health Insurance Premium Program patient handbook and review Appendix 1: GMS Patient Profile Registration Guide, which will help you navigate your patient profile registration.

### HIPP post-kidney transplant GMS resources

You can find instructions on navigating GMS for post-transplant patients at the "Learning Center" in GMS. Use the "Transplant" tag, which groups all GMS resources for AKF's assistance post-transplant.

### How to Contact Us



**GMS Assist:** Visit [GMSassist.com](https://GMSassist.com) to make a phone appointment at a time that is convenient for you.



**Through GMS:** Message us through your GMS account at [gms.KidneyFund.org](https://gms.KidneyFund.org).



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

# AKF's Ambassador Community Engagement Awards program helps Ambassadors make a difference

**A**KF Ambassadors have been doing extraordinary work in their communities lately. Many of these events are made possible through AKF's recently launched Ambassador Community Engagement (ACE) Awards program, which was set up to provide funding for educational events for kidney disease, including rare kidney diseases, in-person or online.

In the first year of the program, AKF provided 10 Ambassadors with ACE Awards. Here are three of those Ambassadors and their events:



## Artise Carr Chicopee, Massachusetts

"About two years ago, I decided to make kidney awareness t-shirts and sell them at farmer's markets and give them to dialysis patients," Artise said. "After I applied for and received an ACE Award, I used that funding to hold an event at my church, where I told people about my journey with kidney disease and discussed how we can improve kidney awareness in our community. I was honored to have the mayor of my city present at that event."



## Tamara Walker Athens, Georgia

"Receiving an ACE Award opened up avenues of communication between myself and my community," Tamara said. "I had asked my mayor to sign a proclamation to declare March as Kidney Disease Awareness Month in my town, and his office was

wondering if there would be an event to accompany the declaration to share information about kidney disease with residents. AKF's ACE Award provided us with funding to hold a session on kidney disease, high blood pressure and diabetes at a community church, and to aid with radio advertisements on local stations. I was also able to make and print important informational handouts for the attendees."



## Sharron Rouse Fort Washington, Maryland

"[The organization I founded], Kindness for Kidneys, hosted a gallery walk to showcase facts about kidney disease, dialysis and transplantation, and our journey as a nonprofit organization. We joined forces with Infinite Legacy, a nonprofit organization

dedicated to saving and enhancing lives through organ and tissue donation, and they set up a table [at the event] to register participants who were interested in becoming organ donors. We applied for an ACE Award to help offset some of the costs for the event, which took place at a local library, and the monetary support contributed to the overall success of the event and enabled us to secure the library room and additional posters for the gallery."

*Interested in becoming an AKF Ambassador? As an Ambassador, you can make an important difference on Capitol Hill, in state legislatures and in your own community. Together, we fight for policies that improve kidney care, protect patients' access to care and increase funding for kidney research. AKF Ambassadors also play a key role in educating elected officials and the media about the impact of kidney disease.*

**For more information on becoming an Ambassador, visit [bit.ly/AKFAdvocacyNetwork](https://bit.ly/AKFAdvocacyNetwork) or use the QR code at right:**





## Learn about AKF's new educational awareness campaigns for two rare kidney diseases

Earlier this year, AKF launched educational awareness campaigns for two rare kidney diseases: complement 3 glomerulopathy (C3G) and IgA nephropathy (IgAN). These campaigns provide patients with information about the diseases and connect them with resources to help them better understand and manage these conditions.

C3G and IgAN are kidney diseases that are related to improper function of the immune system. With C3G, a part of the immune system called the complement system becomes overactive and doesn't work properly, leading to damage and inflammation in the kidneys. This damage prevents the kidneys from filtering toxins out of the blood and can cause kidney failure in about half of the adults who are diagnosed with the disease. IgAN causes kidney damage when a person's immune system produces abnormal antibodies in the kidneys that trigger

inflammation and reduce the ability of the kidneys to filter waste and fluid from the bloodstream, which can eventually lead to kidney failure.

AKF has created dedicated webpages for these campaigns on its main website, [KidneyFund.org](https://www.kidneyfund.org). These pages provide information about diagnosis, symptoms and management, as well as resources for building and managing relationships with a medical team, nutrition considerations, coping with the mental health impacts these diseases can have on patients and their families, and more.

Visit the C3G webpage at [bit.ly/C3GWebpage](https://bit.ly/C3GWebpage) and the IgAN webpage at [bit.ly/IgANWebpage](https://bit.ly/IgANWebpage).

*The C3G and IgAN awareness campaigns are sponsored by Novartis.*



## Love me as I am: Dating on dialysis

It's no secret that dating can be stressful. Finding "the one" can take time, effort and patience, and it can be quite nerve-wracking. But for people living with kidney disease, that nervousness can be magnified several times over.

Jamie Smythe, an AKF Ambassador, said her biggest challenge dating while on dialysis was the fact that many people she went on dates with had little or no knowledge of dialysis and kidney disease in general. "I would tell them that when I was 23 years old, I woke up spitting up blood and was in complete kidney failure," she said. "I'd say, 'as shocked as you are to hear it, I'm just as shocked to have gone through it.'" Jamie would then explain that she had to spend multiple hours a week on a machine that functioned as her kidneys because her real kidneys did not work. "That was the simplest, easiest way that I could convey to them that I was different from others they were dating," Jamie said.

Dawn Cerruto, also an AKF Ambassador, discussed the value of asking your date questions to get a better sense of how they would handle being the partner of someone with kidney disease. "I would ask, 'How would you feel about going to sit with me in the hospital should I spur

of the moment need to go?'" Dawn said. "I had enough self-esteem to [recognize] that if somebody wasn't going to go sit with me and be with me [at the hospital], then maybe they're not worth it."

But while talking about your journey with kidney disease is important, Jamie advised people on dialysis and in the kidney community to remember that they are more than simply their illness. "[Who I am] includes my disability, but I want [my dates] to learn 'me' first," Jamie said. "I would show my strengths, characteristics and my personality and wait until [my dates] were opening up a little bit more and being more transparent about what they desired and what they were looking for, and then I would share my circumstances with them."

Although people with kidney disease have more factors to consider when it comes to dating than people without kidney disease, the main takeaway is the same: don't settle for less and wait for the person who loves and accepts you exactly as you are.

To read the full blog post about dating on dialysis, visit [bit.ly/DatingonDialysis](https://bit.ly/DatingonDialysis).

# 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<sup>®</sup> (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](http://www.fda.gov/medwatch).
- Before taking Velphoro, tell your doctor if you are pregnant, plan to become pregnant, or breast-feeding.

Velphoro is available by prescription only. For additional Safety Information, please see Full Prescribing Information at [Velphoro.com](http://Velphoro.com).

**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/](http://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](http://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](http://www.fmcna.com/patents)

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# AKF staff spotlight



**Name:** Sadaf Shafique

**Hometown:** Riyadh, Saudi Arabia

**What do you do at AKF?**

I am the assistant to the vice president of patient support and education and am responsible for providing high-level administrative

support and monitoring the Office of Patient Support and Education's operations on a daily basis. This includes creating schedules, organizing meetings and facilitating internal and external communication.

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

I am passionate about this cause because it affects

millions of people globally and causes major health issues. By raising awareness, funding research and covering treatment-related expenses, AKF makes an impact on improving the quality of life for individuals suffering from kidney disease and saves lives!

**What is the best part of your job?** The best part is having the opportunity to contribute to positive change while using administrative skills to support the organization's goals. Additionally, working closely with the leadership team at AKF brings me a greater sense of purpose and satisfaction, since I know our efforts are making a noticeable impact on people's lives.

**What are your favorite hobbies outside of work?** Painting and making resin artwork are two of my favorite hobbies. Aside from that, I enjoy going to historic towns and antique shops with my husband and giving my two cats, Mirza and Riley, lots of love and cuddles.

## Kidney Kitchen®



This and other recipes can be found at [kitchen.kidneyfund.org](https://kitchen.kidneyfund.org).



### Ingredients:

- |                                     |  |
|-------------------------------------|--|
| 8-ounce dry rotini or fusilli pasta | 2 teaspoons dried oregano              |
| ½ pound chicken breast              | ⅓ cup fresh basil, chopped and divided |
| ¼ cup red wine vinegar              | ¼ cup parmesan, shredded               |
| ½ cup olive oil                     | ¼ cup mozzarella, shredded             |
| 1 teaspoon (1 clove) garlic, minced | 1 ounce roasted red peppers, chopped   |
| ¼ teaspoon pepper                   | 2 tablespoons capers, rinsed           |
| 1 teaspoon sugar                    |  |

### Directions:

1. Cook pasta according to directions on the package. When cooked, run under cold water until cool. Set aside in a large bowl.
2. Heat a pan over medium-high heat. Split the chicken breast in half lengthwise. Cook the chicken on both sides until browned, then reduce heat to medium-low and finish cooking until chicken reaches 165°F. Move to a cutting board to rest 5 minutes.
3. Place the vinegar, oil, garlic, pepper, sugar, oregano and half the basil into a sealed container. Shake for 15 seconds then set aside.
4. When chicken is cool, dice into small pieces and add to the pasta.
5. Add the remaining basil, parmesan, mozzarella, red peppers and capers to the chicken and pasta.
6. Shake the sauce container vigorously for 15 to 30 seconds then quickly pour over the pasta. Toss to coat all and chill for 1 hour.
7. Serve 1 cup per person.

### Summer Antipasto Pasta Salad

**Makes:** 5 Servings

**Serving size:** 1 cup



**Prep time:** 15 min

**Cook time:** 25 min

**Chill time:** 1 hour

Recipe contributed by Satellite Healthcare



### Cooking Tip:

Don't overcook the pasta, boil until pasta is 'al dente' (meaning tender but firm).

### Nutrition facts

(1 serving = 1 cup)

Calories = 405  
Carbohydrates = 27 g  
Sugar = 1 g

Fiber = 0 g  
Calcium = 205 mg  
Fat = 23 g

Saturated Fat = 2 g  
Trans Fat = 0 g  
Protein = 10 g  
Phosphorus = 280 mg

Cholesterol = 35 mg  
Sodium = 275 mg  
Potassium = 160 mg

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[KidneyFund.org](http://KidneyFund.org)

Help us fight kidney disease.  
Text **KIDNEY** to **52886** to join our mobile Advocacy Network.

## What's Inside:

- Kidney Action Summit brings AKF Ambassadors to Capitol Hill to advocate for kidney patients and living donors
- Join AKF's Rare Kidney Disease Action Network
- AKF launches national kidney health equity media campaign
- AKF calls for more awareness and understanding of APOL1-mediated kidney disease
- Reminders from AKF's Patient Support Team
- AKF's new Know Your Kidneys program provides roadmap to better kidney health
- AKF's Ambassador Community Engagement Awards program helps Ambassadors make a difference
- Learn about AKF's new educational awareness campaigns for two rare kidney diseases
- Love me as I am: Dating on dialysis
- Staff spotlight
- Kidney Kitchen® recipe

