



Shante Byrd, Rex, Ga.  
AKF Ambassador

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# AKF in ACTION

Fighting kidney disease and helping people live healthier lives.

**3** All about autosomal dominant polycystic kidney disease (ADPKD)

**4** New living donor protections help bump the national average up a letter grade

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## Navigating AKF's Financial Assistance Programs

In 2021, the American Kidney Fund's (AKF) charitable assistance programs helped nearly 80,000 low-income dialysis and transplant patients in all 50 states, the District of Columbia and every U.S. territory. AKF's financial help makes possible about 7.5% of all kidney transplants in the United States each year. Below are some helpful hints for patients after they have received a kidney transplant.

AKF's largest assistance program is its Health Insurance Premium Program (HIPP). As its name suggests, HIPP helps low-income dialysis patients with their health insurance premiums. Once an existing HIPP recipient gets a kidney transplant, AKF will continue its help until the end of the current insurance plan year. After that plan year ends, HIPP assistance is finished. Patients can then review other grant programs for eligibility, such as the Safety Net Program, Disaster Relief Program, and the Post-Transplant Testing Program.

### FAQ

#### Does AKF offer HIPP after a kidney transplant?

After getting a transplant, AKF will continue charitable premium assistance for the patient for the remainder of their current insurance plan year. Patients are eligible if they: 1) received assistance with HIPP while on dialysis, 2) if they had HIPP assistance for at least 3 consecutive months immediately before their transplant, and 3) if they remain financially qualified. Patients need to notify and update their profile within 90 days of receiving their transplant.

#### What is an Insurance Plan Year?

Insurance plan years are for a 12-month period. Plan years may vary by policy type. Depending on the plan type, it might follow a regular calendar year from January to December or

another period of time, like a fiscal year (July-June). AKF will always assume that the patient's plan year is based on the traditional January through December calendar year unless a patient's insurance paperwork shows otherwise. You may contact your insurance company at any time to obtain written verification of your insurance plan year.

### What are the steps to follow for Post-Transplant HIPP Assistance?

#### 1. Claim your Grants Management System (GMS) account by visiting [gms.KidneyFund.org](https://gms.KidneyFund.org).

- Use the e-mail address and PIN number in your profile. If you do not have access to it, contact [registration@KidneyFund.org](mailto:registration@KidneyFund.org) to either add or update your e-mail address and get your PIN number. In the e-mail, make sure to include the patient's name, date of birth, and transplant date. When successfully claimed, an e-mail verification link will be sent to access the profile. Note: once an e-mail address has been verified, it cannot be changed.


#### 2. Update the "Health Information" section in your profile by adding your transplant date.

#### 3. Update the "Facilities" and "Contacts" section in your GMS profile.

- Contact your transplant center to verify they are registered in GMS and can assist in managing your account. If they can, the transplant center should be

Continued on next page

# Navigating AKF's Financial Assistance Programs, cont.

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able to transfer your profile to their patient list. All facilities and contacts must be registered in GMS before being assigned to a profile. If your transplant center cannot assist, you may manage your own account. A Treatment Center Verification Form located in your profile can be downloaded (please read instructions carefully). Once returned to [registration@KidneyFund.org](mailto:registration@KidneyFund.org), AKF will update the facility and contact information.

## 4. Check for existing grant requests/pending payments.

- Be sure to verify that all payment information is correct before confirming a payment. If there are no payments in GMS, you might need to submit a new grant request. Refer to the "How to Confirm a Payment" guide located in the "Information" tab.

## 5. Submit a grant request.

- For HIPP assistance to continue, a current bill (no older than 90 days) is required. Check that your insurance plan year(s) for the policies that AKF was already assisting with falls within the current requested year of assistance. AKF needs 10–14 business days to process a correct and completed request. Once approved, grants are often issued within 3–5 business days. Payments will not be issued earlier than 45 days before the coverage start date and processed on the availability of funds.

**Can AKF enter a request on my behalf?** No, all requests are submitted in GMS by the patient, a renal professional or a family caregiver.

**How do I submit a new grant request?** To submit a new grant request, a bill no older than 90 days is required. A guide to submit a request can be found under the "Information" tab within GMS. When the request has a "Pending Review" status, it will then be reviewed by our team on a "first-come, first-served" basis.

**I do not see the "Apply Now" button to submit a new HIPP request. What do I do?** Please be sure that: 1) your profile has been updated, 2) your consent forms are not expired, and 3) all information on the profile is completed and verified. Consent forms can be downloaded from the

"Documentation and GMS Agreements" tab or can be signed digitally (via patient GMS account only). Please contact Patient Support for further assistance if the "Apply Now" option is still unavailable

**How do I update incorrect payment information?** If any payment information is incorrect or needs to be updated, the payment should not be confirmed. Instead, those payments should be cancelled, and a new, corrected request should be submitted.

**Are there instructions in GMS?** There are "how-to" guides to submit a request, confirm a payment and other instructions available to download in the "Information" tab within your GMS account.

The American Kidney Fund (AKF) fights kidney disease on all fronts and assists qualified dialysis patients through financial assistance programs. More information can be found at [KidneyFund.org](http://KidneyFund.org) under "Get Assistance."

Our largest program, HIPP, assists qualified patients in paying for medical insurance premiums. Please take some time to learn about the program by visiting [KidneyFund.org/get-assistance/health-insurance-premium-program-hipp](http://KidneyFund.org/get-assistance/health-insurance-premium-program-hipp). You can download the HIPP guidelines and the HIPP patient handbook for more information on available assistance and eligibility criteria.



## How to Contact Patient Support:

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



**GMS Assist:** Visit [GMSassist.com](http://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](http://gms.KidneyFund.org). Be sure to also check the "Information" and "FAQ" tabs for more updated information.



**Phone:** Call us at **1.800.795.3226** Monday through Thursday to speak with a live representative. Please do not send messages, voicemails or emails to other departments to request a call back as they will not be processed.



**Online:** Visit [KidneyFund.org](http://KidneyFund.org) to learn more about AKF's financial assistance programs.



**GMS registration issues:** Email us at [registration@KidneyFund.org](mailto:registration@KidneyFund.org).

# All about autosomal dominant polycystic kidney disease (ADPKD)

**A**utosomal dominant polycystic kidney disease (ADPKD) is a genetic disease that causes cysts to grow inside the kidneys. These cysts make the kidneys substantially larger than they should be and damage the kidneys' tissue. Over time, ADPKD can lead to kidney failure. About half of people with PKD will have kidney failure by age 60, and about 2% of new cases of kidney failure are caused by ADPKD.

To increase awareness of the disease and resources for those living with or at risk for ADPKD, AKF has launched an ADPKD education and awareness campaign. Through this campaign, AKF will:

- Expand general awareness of PKD, but with a heightened focus on ADPKD
- Educate people on dialysis and their families about the risk of rapid progression in PKD and the importance of seeking treatment
- Empower people diagnosed with ADPKD to talk to their families about the genetic link to the disease, and the importance of getting screened
- Ensure we are including the needs of underrepresented populations, including communities of color, who may be at risk for PKD
- Address the mental health impact of PKD/ADPKD (anxiety, depression, fear, isolation) and ensure that people with the disease know they are not alone, directing people to support resources

To find out if you have ADPKD, talk to your doctor. They can perform imaging tests, such as CT scans, MRI scans and ultrasounds to look for cysts, as well as perform genetic tests using a sample of your blood or saliva. If ADPKD is detected, be an advocate for yourself and maintain ongoing, open communication with your doctor. Ask them about your total kidney volume and where you are in your disease progression. While there is no cure for ADPKD, your doctor can work with you to help you manage your condition and keep your kidneys working longer, which can delay the need for dialysis or a transplant.

For more information on ADPKD and the campaign, visit [KidneyFund.org/ADPKD](https://KidneyFund.org/ADPKD).

*The ADPKD Education and Awareness Initiative Campaign is generously supported by Otsuka America Pharmaceutical, Inc.*



## Finding community at Camden Yards

Scorching heat and ominous skies were no match for AKF's first camp picnic held at Camden Yards on July 16 for children with kidney disease and their families. About 200 people gathered in person for the first time since the beginning of the COVID-19 pandemic. Thankfully, the rain held off, and families enjoyed music, food, and arts and craft stations. AKF was thrilled to be able to provide an in-person experience for this special group, who often feel isolated and face many challenges due to the life-altering nature of kidney disease.



## AKF staff spotlight



**Name:**  
Marcia Wright-Alston

**Hometown:**  
Washington, DC

**What do you do at AKF?**  
I am the Patient Support Coordinator. I assist patients by processing

grant requests via our Grants Management System in order to help pay their health insurance premiums. I also help them by assisting in navigating and troubleshooting in GMS, in addition to providing customer service by phone.

**What is your connection to kidney disease?** I have family members on dialysis. On my first day at AKF 16 years ago, we found out my sister-in-law was diagnosed with kidney failure and had to immediately go on dialysis. My brother is also awaiting his second transplant.

**Why are you passionate about fighting kidney disease?** If there were no AKF, the patients we serve would not be able to pay their insurance premiums in order to get the treatments and care they need. AKF makes a difference in taking some of the stress and anxiety out of having kidney disease.

**What is the best part of your job?** The best part of the job is the relationship I have with the people in the kidney community that we serve. Sometimes I think that when I help them, I am also helping myself knowing that I can make a small difference in their lives.

**What are your favorite hobbies outside of work?** My favorite hobbies are crocheting, reading, talking on the phone and more crocheting.

## New living donor protections help bump the national average up a letter grade

There was a renewed push earlier this year for laws that protect living organ donors, with eight states enacting new legislation. Between April and June, Florida, Ohio, Virginia, Nebraska, Delaware, Georgia, Louisiana and Minnesota passed laws increasing living donor protections. With these laws, each state's grade on AKF's State of the States Living Donor Protection Report Card ([livingdonor.KidneyFund.org](https://livingdonor.kidneyfund.org)) was raised a letter, which ultimately brought the national grade average up from a D to a C—promising news for people on the transplant waiting list, and the people who wish to donate a lifesaving organ.

AKF's Report Card assigns each state a letter grade from A to F based on how well their existing laws encourage living organ donation and lessen barriers for living donors through policies such as anti-insurance discrimination laws, tax credits for donor expenses and job-protected leave. AKF has been on the frontlines at the state and federal levels to secure these critically important protections.

While the increase in the U.S.'s national grade average is promising, there is still much more that needs to be done for the nearly 106,000 people waiting for an organ transplant—including the nearly 90,000 who are waiting for a kidney. Because where Americans live should not impact their ability to give the gift of life. Through the AKF Living Donor Protection Report Card, we hope to continuously shine a bright light on the states that are making progress to encourage living donation while pushing other states to enact legislation to protect living organ donors.

Although we have made great strides, there is still much more we can do as a nation to protect living donors and encourage more people to become living organ donors. This includes the federal government enacting policies, such as the Living Donor Protection Act (H.R. 1255/S. 377), that remove barriers to living donations for all Americans. For more information on the American Kidney Fund's Report Card, visit [livingdonor.KidneyFund.org](https://livingdonor.kidneyfund.org).



## New resources on itchy skin (pruritus) for patients

Visit [KidneyFund.org/itching](https://KidneyFund.org/itching) for information on kidney disease-associated pruritus, what causes it and how to talk with your doctor about treatment.

Educational content made possible by



# Kidney Kitchen®

You will be surprised how delicious and creamy the sauce becomes in this dish. It is quite addicting, yet it is a healthy way to enjoy a “creamy” style pasta. Check out many more kidney-friendly recipes at [kitchen.KidneyFund.org](http://kitchen.KidneyFund.org). On Kidney Kitchen®, you’ll find guides for kidney-friendly eating at every stage. For specific questions you may have, talk with a dietitian (nutrition expert) to make a meal plan that’s unique to you.



## Spaghetti with Cauliflower Cream and Spicy Breadcrumbs

**Makes:** 6 low-sodium servings, 1.5 cups each



**Prep time:** 20 min  
**Cook time:** 15 min

Recipe contributed by  
FamilyCook Productions



**Cooking Tip:** Pasta water is key for creating a luxurious smooth pasta sauce. The water, which the pasta was cooked in, contains leftover starch from the boiling noodles. When this is added to the pan with your pasta and other ingredients, it causes the sauce to thicken and adhere to the pasta.

### Ingredients:

- 3 tablespoons extra-virgin olive oil
- ¾ teaspoon red pepper flakes
- ⅓ cup (20 grams) breadcrumbs, plain
- ⅓ cup parsley, chopped
- ½ cup (65 grams) cashews, raw, unsalted, roughly chopped
- Pinch black pepper, freshly ground
- ½ cup (80 grams) shallot, thinly sliced (from 4 small shallots)
- 2 gloves garlic
- 1 cup water
- ½ head (428 grams) cauliflower, in florets
- 1-ounce (30 grams) pecorino Romano cheese, grated (about ⅓ to ½ cup)
- 1 tablespoon heavy cream
- ¾ pound linguini
- Pinch black pepper, freshly ground

### Directions:

1. Heat a large skillet over medium-high heat.
2. Add 2 tablespoons of olive oil and red pepper flakes. Reduce heat to medium-low for about 2 minutes. Pour 1 tablespoon of the chili oil in a small bowl to reserve for use later.
3. Add the breadcrumbs into the skillet with the remaining chili oil. Cook, stirring until breadcrumbs are golden, about 4 more minutes.
4. Transfer breadcrumbs to a small mixing bowl. Stir in parsley and ¼ cup of chopped cashews; season with black pepper and reserve.
5. Heat the same skillet over medium heat. Add the remaining 1 tablespoon of olive oil and the sliced shallot.
6. Cook, stirring frequently, until the shallot is softened, about 3 minutes.
7. Add the garlic and cook, stirring until fragrant, about 2 minutes more.
8. Pour 1 cup water into the skillet. Add the cauliflower and bring to a boil.
9. Reduce heat to medium, cover and cook cauliflower until tender, about 5 minutes.
10. Transfer the cauliflower mixture into a blender, along with cheese, heavy cream, remaining ¼ cup cashews, and reserved chili oil. Process until smooth and creamy.
11. Cook the linguini following package instructions or until it is al dente or slightly chewy and not too soft. Reserve ½ cup pasta water and drain pasta.
12. Return pasta to pot. Add a couple tablespoons of pasta water. Toss to coat pasta well. Add the cauliflower puree; season.
13. Divide into 6 bowls (approximately 1.5 cups each). Sprinkle with breadcrumbs/cashew mixture. Enjoy!

### Nutrition facts (1 serving = 1.5 cups)

Calories = 400  
Carbohydrates = 55 g  
Sugar = 6 g

Fiber = 4 g  
Calcium = 85 mg  
Fat = 15 g

Saturated Fat = 3 g  
Protein = 13 g  
Phosphorus = 249 mg

Cholesterol = 7 mg  
Sodium = 100 mg  
Potassium = 490 mg

## THE 37 MILE CHALLENGE

You can directly help the 37 million Americans living with kidney disease by challenging yourself to walk/run 37 miles this spring.

To start your challenge, contact Martin McNutt at [mmcnutt@kidneyfund.org](mailto:mmcnutt@kidneyfund.org) or (240) 292-7056.

[www.KidneyNation.org/37-mile-challenge](http://www.KidneyNation.org/37-mile-challenge)



11921 Rockville Pike  
Suite 300  
Rockville, MD 20852  
800.638.8299

**KidneyFund.org**

Help us fight kidney disease.  
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## What's Inside:

- Navigating AKF's Financial Assistance Programs
- All about autosomal dominant polycystic kidney disease (ADPKD)
- AKF staff spotlight
- New living donor protections help bump the national average up a letter grade
- Finding community at Camden Yards
- Kidney Kitchen recipe