



SPRING 2022 | VOL. 7.1


AKF in ACTION


Fighting kidney disease and helping people live healthier lives.


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The importance of increasing representation in clinical trials

Clinical trials are research studies that test the safety and effectiveness of new treatments. They are an essential part of the process of developing new medicines, therapies and/or tools for diagnosing and treating diseases, including kidney disease.

To make sure treatments are safe and work for all people, it is important for clinical trials to include people from diverse backgrounds. Historically, Black, Hispanic/Latino, Native American and Asian American people have been underrepresented in clinical trials. This means that compared to the number of people from these communities who are living with kidney disease, few participate in clinical trials. The American Kidney Fund (AKF) has a long history of advocating for health equity, including working to increase diverse participation in clinical trials. As an organization, we are expanding these efforts to further increase awareness of the importance of participating in clinical trials, particularly for communities of color and other underrepresented communities.

If you are unsure about volunteering for a clinical trial and being one

of the first to potentially receive a new treatment, please note that treatments studied in clinical trials go through many rounds of testing before they are tested on people. There are even laws, such as the Clinical Trial Participant Bill of Rights, that protect the safety and privacy of clinical trial participants.

But you may still be asking, “Why should I participate in a clinical trial?” Here are a few great reasons to sign up for one today:

- You may receive these benefits:
 - Access to new and possibly effective treatments or medicines available only to those participating in the trial
 - Low or free treatment costs
 - Focused care for your health condition
 - Learning more about your disease or health condition
- If you participate in a clinical trial, you have the unique opportunity to help society and other people with your disease or health condition while receiving care for your condition.
- Your participation advances understanding of your disease,

which will then help people in the future receive more effective, better treatments.

As a clinical trial participant, you are encouraged to ask the researchers questions about the study you are participating in and bring a family member or friend for support during the treatments. You also always have the option to drop out of the trial for any reason and without penalty.

If you are interested in participating in a clinical trial for people with kidney disease or learning more about clinical trials, we encourage you to:

- Talk to your doctor and the rest of your kidney care team about whether participating in a clinical trial is right for you
- Ask your doctor if they know of any clinical trials you may qualify for
- Use AKF’s tool to find kidney disease clinical trials at **[KidneyFund.org/clinical-trials](https://www.kidneyfund.org/clinical-trials)**
- Search the U.S. government’s online database of clinical trials at [ClinicalTrials.gov](https://www.clinicaltrials.gov)

AKF’s educational content around increasing engagement in clinical trials among underrepresented communities is made possible with support from GSK.

How to claim and manage your profile in GMS

As someone who receives financial assistance from AKF, you have a profile, or account, in our Grants Management System (GMS). Through your GMS profile, you can do things like access your past and current payments from AKF, submit grant requests and more.

If you have not done so already, please claim your profile so you can access your account information and use all the features in GMS. You will need your PIN and the email address associated with your profile in order to access it. If you do not know your PIN, please email us at registration@KidneyFund.org or call **1.800.795.3226**. Once you have your account's email address and PIN, please follow the steps to claim your profile:

1. Go to GMS at gms.KidneyFund.org and click **"Register"**
2. Click on **"Let's Get Started"**
3. In the **Patient** box, click on **"I have a PIN to claim my account"**
4. Enter your **email address** and **PIN**
5. Complete the **"Adding Your Account Credentials"** section to create a username and password and answer the security questions, including selecting a security image
6. Click on **"Claim My Account"** at the bottom right when done
7. You will receive an email with a verification link. Please click on this link, as verifying your account will allow full access to your profile and the ability to enter a new grant request.

What can I do after claiming my account?

By claiming your account, you can submit a grant request, review payments, confirm payments, verify your eligibility, send us a message and more.

Instructional guides on how to manage your account can be found in GMS after claiming your profile. Please visit the **"Information"** tab in the top menu bar to browse and search for our guides.




If you are living with a transplant, you can find the guide **"What to Do After Transplant"** in the **Information** tab.

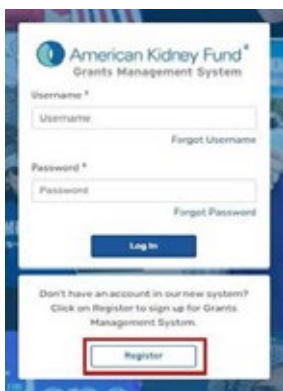
You can find the complete list of documents available by searching **"Index"** in the **Information** tab.

How to search for guides (see image on next page):

1. Search for a guide or resource, such as **"How to submit a grant request"**
2. Click **"Apply Filter"**
3. The relevant documents will display. Click **"Read More"** to download the document.

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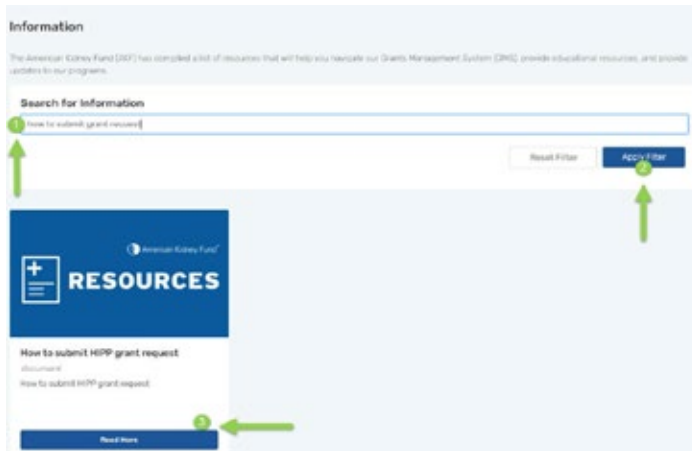


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Managing your GMS profile, cont.


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Please check “**Frequently Asked Questions (FAQ)**” for updated information. This can be found in the Information tab by searching “**Frequently Asked Questions**” or “**FAQ.**”


? Questions?

If you have any questions about AKF’s financial assistance programs or need help using your GMS account, please contact AKF’s patient services department:

 **Phone:** Call us at **1.800.795.3226** from 9 a.m. to 5:30 p.m. ET Monday through Thursday, and from 9 a.m. to 3 p.m. ET on Friday. Please call during business hours to speak with a live representative. To protect your privacy, voicemails are not accepted or responded to.

 **GMS Assist:** Visit **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**. Be sure to also check the information and FAQ sections of your account for up-to-date information.

 **Online:** Visit **KidneyFund.org** to learn more about AKF’s financial assistance programs.

 **GMS registration issues:** Email us at **registration@KidneyFund.org**.

— AKF staff spotlight



Name:
Ben

Hometown:
Rockville, Md.

What do you do at AKF?

I’m the associate director of

government relations at AKF. I work with all of our wonderful AKF Ambassadors and provide them with various opportunities to get engaged in kidney disease advocacy on the federal and state levels. I hope you’ll join us at **KidneyFund.org/ambassadors**.

What is your connection to kidney disease?

I didn’t know this when I started at AKF, but my maternal grandfather died from kidney disease. My uncle, who recently passed away, was on dialysis and had trouble with diabetes.

Why are you passionate about fighting kidney disease?

In my years at AKF, I have become very close to our Ambassadors. I truly internalize their stories and experiences. For me, fighting kidney disease means fighting on behalf of our Ambassadors.

What is the best part of your job?

Our Ambassadors, hands down. It is a privilege to get to work with such a dedicated, knowledgeable and hard-working group of folks.

What are your favorite hobbies outside of work?

I have two daughters, who are five and two-and-a-half years old. My favorite thing to do is spend time with them—whether we are taking a day trip to the zoo or a museum, or watching “Encanto” for the thousandth time!



We’ve redesigned our website to make it easier for you to use.

Visit the new KidneyFund.org!



Above: Adam (left) and Zach (right)

The ripple effect of becoming a living kidney donor

Growing up in a household of sisters, Adam Ciperski was excited to welcome his twin brothers, Zach and Blake, into the world. Almost immediately after the twins were born, the brothers quickly developed a special relationship. Ten years their senior, Adam always looked out for his younger brothers, including decades later when he donated his kidney to Zach.

It came as a surprise to the Ciperski family when Zach's annual sports physical during his senior year of high school revealed that the all-state hockey goalie had IgA nephropathy. "We were in a bit of shock," Adam remembers. "You wouldn't expect a rare disease like this to happen to such a young, healthy and athletic person. It really sent a wave through the family."

When Zach's kidneys began to fail after his freshman year of college, the family jumped to get tested to see if any of them could become a living kidney donor. When the tests revealed that Adam was the best match for Zach, he knew right away that he would donate his kidney. "I guess it was

an older brother thing. There was just no doubt in my mind that I would help," Adam explains.

On Oct. 5, 2000—a few weeks shy of Zach's 20th birthday—the brothers underwent the transplant surgery at Columbia Presbyterian Hospital in New York. Adam remembers that after the surgery, Zach "instantly got better." In fact, Zach was the one to visit Adam's bedside in the hospital.

Meanwhile, Adam's recovery process was a bit harder on him because his living donor transplant surgery was more invasive than the common laparoscopic procedure done today. For Adam's surgery, a big incision was made, and the surgeon even removed a couple of his ribs to make it easier to take out his kidney. With the less invasive laparoscopic surgery, the surgeon instead uses very small incisions and a thin, lighted tube to look inside the body.


"I think that was the part I didn't anticipate as much," Adam says of his recovery. "I was kind of ready for it, but coming out of the surgery, it really did take a lot out of me. I've become friends with other living donors, and they're like, 'I've just got these little incisions you can barely see. The kidney came out and I was fine the next day.'" Adam says he has "a big 'C' incision that looks like I got bit by a shark. A friend of mine told me it's a great scar to have while I'm at the beach."

But after the surgery, Adam and Zach's beach days were still a while off. They both hunkered down at their parents' home in New Jersey to watch a steady stream of Blockbuster rentals while they recovered together. "If we were to do it today, we could probably keep Blockbuster in business," Adam jokes. "We would watch three or four movies a day. My dad would get home from work and his first task would be go to Blockbuster to change out those movies."

Today, Adam says that he is more than fine living with one kidney. In fact, he is a triathlete and a four-time Ironman. "After a couple months, you wouldn't know anything is different."

Although Adam had no hesitations about donating his kidney, Zach was worried that he would feel constantly indebted to his older brother. Adam was adamant about putting those concerns to rest and told his brother, "Your only obligation to me is live long, healthy and happy. If you do that, then that's my reward."

Every year on the anniversary of their transplant surgeries, Zach sent Adam a letter highlighting all the things he was able to accomplish that year because of Adam's lifesaving gift. Adam saved each letter in a journal as a written record of the impact of becoming a living kidney donor.

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Kidney donor, cont.

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Adam's gift of a kidney extended Zach's life by an additional 13 years. Between the time of the transplant and his death on Jan. 26, 2014, Zach lived an incredibly full life. He went on to complete college, earn his master's degree, begin a successful career and travel the world, visiting Europe, Asia

and Central America. He also became involved with Fabretto, a nonprofit that helps underserved children in Nicaragua gain access to education. "Zach was able to create this sustaining legacy," Adam says. "After his passing, a library was established in Nicaragua in his name."

For Adam, his brother is just one example of the positive impact of becoming a living kidney donor.

"He got a ton done in his extra 13 years. To me, that is the ultimate blessing and the thing I cherish," Adam says of Zach. "And now all these kids go to his library, so he is having a positive impact on people through the work he did post-transplant. That's the beauty of it and that's why you donate. Donating creates a ripple effect—look at all the lives he continues to touch because he got those extra years."

Kidney Kitchen

This mac 'n cheese has a secret ingredient for an extra creamy and nutritious sauce—cauliflower. Topped with a flavorful pesto, this version is high in flavor while low in sodium, making it a winner. Check out many more kidney-friendly recipes at [KidneyFund.org/kitchen](https://www.kidneyfund.org/kitchen). As always, please speak with your doctor and dietitian to come up with a food and fluid plan that is healthy for your unique needs.




Creamy Mac 'n Cheese with Kale Pesto

Makes: 6 low-sodium, low-potassium, medium-phosphorus, medium-protein servings

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

Recipe contributed by
FamilyCook Productions

 **Tip:** Reserve some of the water the pasta was cooked in and use a splash to thin out the cheese sauce, if needed.

Ingredients:

2 cups (42 grams) kale, chopped
¼ cup walnuts, unsalted
2 tablespoons parmesan cheese, grated
2 garlic cloves
1 tablespoon lemon juice
6 tablespoons olive oil
12 ounces tri-color or farfalle pasta (or other pasta shape)
¼ cup milk, whole fat

1 tablespoon butter, unsalted
1½ ounces cream cheese, room temperature
2 ounces cheddar cheese, shredded
¼ teaspoon paprika
1 cup (107 grams) cauliflower florets

Special Equipment:

Food processor/blender

Directions:

1. Combine kale, walnuts, parmesan cheese, garlic cloves and lemon juice in a food processor or blender.
2. Process until ingredients become paste-like. Add olive oil in a drizzle with the motor running.
3. Transfer kale pesto to a bowl and set aside.
4. Cook pasta according to package directions.
5. Combine milk, butter, cream cheese, cheddar cheese, paprika and cauliflower florets in a medium saucepan over medium-high heat.
6. Heat to a boil and reduce heat. Simmer for 6 to 8 minutes, stirring occasionally, until all the cheese has melted and the cauliflower is fork tender.
7. Transfer the cheese mixture to a food processor or blender. Process until smooth and creamy.
8. Toss cheese sauce with cooked pasta in a large serving bowl until evenly coated.
9. Divide the mac 'n cheese into 6 individual bowls, 1 cup per portion. Top each serving with 2 tablespoons of pesto.

Nutrition facts

(1 serving = 1 cup + 2 tablespoons pesto)

Calories = 468
Carbohydrates = 46 g
Sugar = 3 g

Fiber = 3 g
Calcium = 145 mg
Fat = 26 g

Saturated Fat = 7 g
Trans Fat = <1 g
Protein = 12 g

Phosphorus = 212 mg
Cholesterol = 22 mg

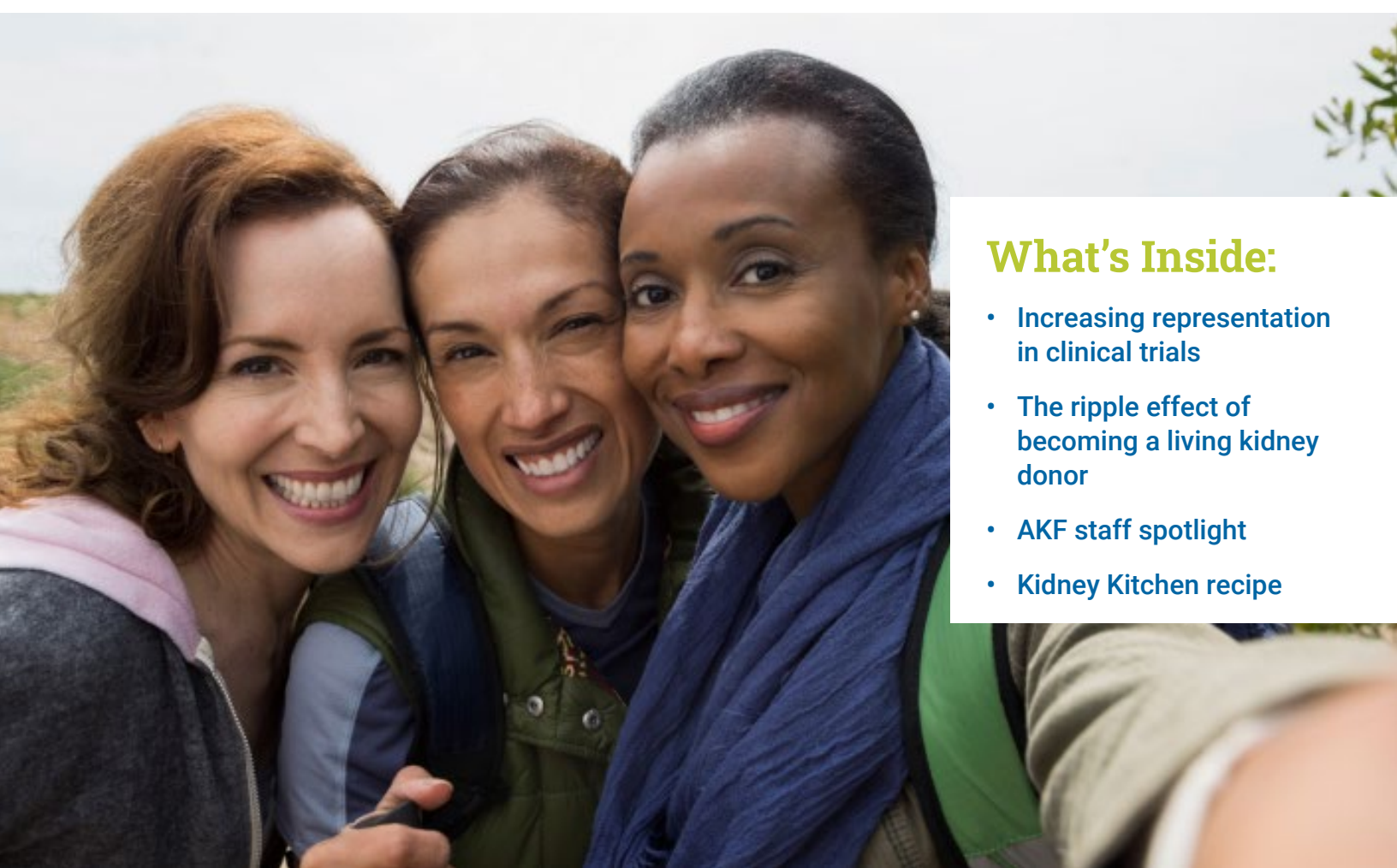
Sodium = 139 mg
Potassium = 268 mg



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KidneyFund.org

Help us fight kidney disease.
Text **KIDNEY** to **52886** to join our mobile advocacy network.



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