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AKF Ambassador



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AKF in ACTION

Fighting kidney disease and helping people live healthier lives.

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APOL1 101: All About APOL1-mediated kidney disease (AMKD)

While everyone has two copies of the APOL1 gene, those with two variants, or mutations, have an increased risk for kidney disease. Unfortunately, awareness of the link between APOL1 gene mutations and kidney disease is relatively low. Read on to learn if you may be someone who should get tested for the APOL1 gene variants.

Genes are in the part of your cells that contain DNA and are passed down (inherited) from parents to children, including genes that have a change or variation, known as a mutation. The APOL1 gene makes a protein that helps your immune system, which fights off infections in your body. However, if you inherited a mutation in both of your APOL1 genes, this mutation can cause damage to parts of your kidneys that filter blood, and can sometimes lead to cells in your kidneys dying. When cells die, it causes damage and scarring in the kidneys that can lead to kidney failure.

It is estimated that one in five people with mutations on both copies of their APOL1 gene will get kidney disease, known as APOL1-mediated kidney disease (AMKD). The changes to the APOL1 gene were originally a protective mutation against a parasite in Western or Central Africa that was passed down through generations. Therefore, if you are of African descent, it is important to get a genetic test for the APOL1 mutations. And if you do have the APOL1 gene variants, you may want to ask your family members (parents, siblings, children) to get tested, as these variants can be passed on in families. The sooner you know, the better you can manage your health and lifestyle in hopes of preventing kidney disease.

You are more likely to have APOL1 gene mutations if you are from Western or Central Africa or have an ancestor who came from these regions. This may include people who

identify as Black, African American, Afro-Caribbean and Latina/Latino.

AMKD is a progressive disease and can get worse over time. Although currently there are no medicines available for AMKD, there are clinical trials in process to study potential new treatments. In the meantime, if you or a loved one have been diagnosed with kidney disease or AMKD, it is critical for you to follow your doctor's treatment plan. Through management of your health and lifestyle, you may be able to slow progression of your kidney disease and prevent the need for dialysis or a kidney transplant.

If you have AMKD, be sure to find a kidney doctor (nephrologist) you trust. Measure your blood pressure each month and write the number down to bring to your doctor's appointments. Once a year, ask your doctor to check your kidney function with a urine and blood test.

To help keep yourself healthy if you have AMKD, you should take the following steps:

- Follow a healthy eating plan. This may include lowering the amount of salt (sodium) you eat.
- Take all of your prescription medicines the way your doctor tells you to.
- Be active for at least 30 minutes a day on most days of the week.
- Quit smoking or using tobacco.

For more information about APOL1-mediated kidney disease, talk with your doctor and visit our website at [KidneyFund.org/APOL1](https://www.kidneyfund.org/APOL1).

This APOL1-mediated kidney disease education campaign is sponsored by



Kidney Health for All: AKF launches health equity website

As part of our mission to fight kidney disease and help people live healthier lives, the American Kidney Fund (AKF) has made tackling health disparities in the kidney community a top priority. Our recently launched website, [KidneyHealthForAll.org](https://www.kidneyhealthforall.org), is the latest project within this effort.

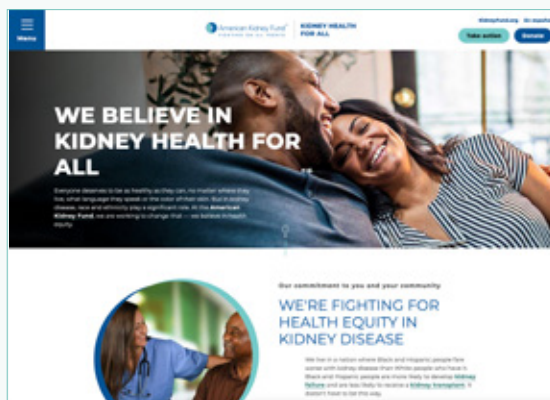
The site will serve as a hub for AKF's education and outreach efforts that are focused on health equity, race and kidney disease. It centers around the four pillars of AKF's health equity initiative:

- 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, as an available treatment option

- Increasing access and removing barriers to kidney transplantation among people of color

Kidney Health for All was developed with input from AKF's Health Equity Coalition, which is made up of nearly two dozen organizations and leaders that advise and help guide the development of evidence-based programs and resources for AKF. AKF also collected firsthand experiences and insights from AKF Ambassadors.

Kidney Health for All was developed with critical early support from Presenting Sponsor AstraZeneca. Additional support was provided by Presenting Sponsors Boehringer Ingelheim and Eli Lilly and Company, Travers Therapeutics, Inc., Vertex Pharmaceuticals; Equity Sponsor Otsuka America Pharmaceutical, Inc.; and Merck.



We want you to become AKF Ambassadors!

At the American Kidney Fund, we are fighting kidney disease on all fronts for the 37 million Americans who have kidney disease, and the millions more at risk.

One of the important ways we fight is through our advocacy. AKF works in the regulatory, state, and federal policy arenas to advocate for laws and rules that will help improve health outcomes for people with kidney disease. AKF Ambassadors play an integral role in our advocacy, particularly in our state and federal policy work.

Our ambassadors contact elected officials to educate and inform them on issues supporting kidney health. Some AKF Ambassadors also meet with elected officials and media to discuss pending legislation. AKF Ambassadors provide important firsthand experience of the challenges we are seeking to highlight and overcome on the path to health.

For example, New York Gov. Kathy Hochul recently signed the New York State Living Donor Support Act to provide direct reimbursement of up to \$10,000 to living

organ donors. This is the first legislation of this kind in the nation—and was helped in part by AKF Ambassadors who urged Gov. Hochul to sign this bill, which could help increase organ donation.

As the new Congress and state legislative sessions begin, AKF will need to do even more to identify champions and elevate kidney issues. With your help, we can provide enough support to pass even more federal and state legislation, ensuring that every person with kidney disease has access to the health care and support they need, at every step of their disease.

If you have not already done so, please take a moment to sign up to become an AKF Ambassador by scanning the QR Code below or join on the American Kidney Fund website at [KidneyFund.org](https://www.kidneyfund.org).

We welcome new AKF Ambassadors from every state but are in particular need of Ambassadors in the following states: Arizona, California, Florida, Indiana, Kentucky, Michigan, Mississippi, Nebraska, South Carolina, Utah, Virginia and West Virginia.

Become an AKF Ambassador



SCAN HERE



Helping to 'kick' kidney disease: Steelers punter Pressley Harvin III raises kidney disease awareness

When Pittsburgh Steelers punter Pressley Harvin III stepped onto the field on Sunday, Dec. 4, he was sporting a new pair of cleats that meant more than just a new look. The gold and black cleats were designed to honor Pressley's father, Pressley Harvin Jr., who passed away on Christmas Day 2021. "I just told myself I want to make today special," said Pressley, "and the cleats definitely did come in handy for sure because I know I definitely felt [my dad] with me."

Across one cleat was Pressley Jr.'s name, along with three black lines to acknowledge all grandfather, father and son Pressleys. AKF's logo, Pressley's chosen charity for the My Cause My Cleats campaign, appeared on the other shoe.

Through this campaign, NFL players raised awareness of a cause they care about by creating custom cleats with their charity's logo to wear during their week 13 and/or 14 games. Pressley chose AKF as another way to honor his father, highlighting his lifelong battle with kidney disease.

Pressley Jr. was diagnosed with kidney failure when he was 16 years old, after complications from a case of strep throat permanently damaged his kidneys. From that time on, he received dialysis treatments three times a week until he was able to receive a kidney transplant. Pressley Jr. was fortunate enough to receive two transplants during his lifetime and was hoping to receive a third. However, a prostate cancer diagnosis prevented him from remaining on the waitlist and ultimately led to his passing.

Pressley's cleats displayed an image of a heart inside a kidney, a reflection of the literal connection between heart and kidney disease as well as a metaphor for how his family kept perspective on his father's kidney disease.

"We had one less kidney in the house the whole time, but we also knew that we had one big heart in that void of the kidney that my dad didn't have," said Pressley. "And that was the one thing that just kept my family going was putting your heart over your kidneys."

Despite the ups and downs of living with kidney failure, Pressley said that his father kept "fighting the fight" every single day and "found small ways of trying to give back."

"My dad isn't here today, but I didn't want his fight of him trying to help others go to waste or cease when he's not here," explained Pressley. "And I just wanted to give people a little sense of awareness to the cause in general, because it's one of those sicknesses that if it's not in your family or it doesn't pertain just to you individually or you're not affected by it, some people don't really know the severity of it. So just enlightening people, educating them and telling the ones that are sick, the caregivers that give care like my mom did for my dad...I wanted to let their voice be heard... Using my voice and using my platform can go a lot longer ways than just putting it on a cleat in a football game."

In addition to wearing the special cleats, Pressley also participated in AKF's virtual camp for children with kidney disease, making a special appearance during a session dedicated to making gingerbread houses.

Missed Kidney Action Week?

Visit bit.ly/KAW2023Replay for videos of sessions from this virtual event about all matters related to kidney health





AKF Grant Assistance

The American Kidney Fund (AKF) is implementing new requirements for our grant assistance programs. If you are currently receiving assistance from AKF, there are some changes to the grant process that you should be aware of for 2023.

The following are details for AKF's new program eligibility rules starting April 1, 2023:

To qualify for AKF assistance, patients may not exceed a household pretax income of 500% of the Federal Poverty Level (FPL), and liquid assets (excluding retirement accounts) may not exceed \$30,000. We selected 500% of FPL as this is the same or slightly higher threshold used by federal assistance programs. Proof of reported income is required.

AKF requires that you "recertify" by your anniversary date that you are still financially eligible for assistance from AKF. You must update your financial information in your Grant Management System (GMS) profile annually. In 2023, proof of your income will be required at your anniversary date, which can be found within your GMS account information or by asking your social worker.

There are two ways to prove your income:

1. Patients already enrolled in the Low-Income Home Energy Assistance Program (LIHEAP), Temporary Assistance for Needy Families (TANF), Housing Assistance (HUD) or Supplemental Nutritional Assistance Program (SNAP) are automatically eligible once a copy of your current year's approval letter or statement is submitted and approved by AKF.

2. If you are not enrolled or do not have documents showing you are participating in one of the low-income family federal programs, you can also provide:

- A copy of your tax return from the current period
- Social Security award letter or retirement benefit statement
- Two paychecks for consecutive periods no older than 90 days
- An Income Exception Attestation Form may be submitted if you have a reason for being unable to provide one of the other types of documents (reasons accepted are listed within the form)

Post-Transplant HIPP Assistance

After receiving a transplant, AKF may continue charitable premium assistance for the patient for the remainder of their current insurance plan year. Patients are eligible only if they have received assistance with HIPP while on dialysis for at least 3 consecutive months immediately preceding their transplant and if they remain financially qualified. Patients are required and responsible for notifying and updating their profile within 180 days of receiving their transplant.

What is an insurance plan year?

Insurance plan years are a 12-month period and may vary by policy type. Depending on the plan type, a plan year could follow a calendar year from January to December or another period of time. AKF will always assume that the patient's plan year is based on the traditional January through December year unless verified differently by insurance documentation. You may contact your insurance company at any time to obtain written verification of your insurance plan year.

Ways to Contact AKF

Please do not send messages, voicemails or emails to other departments to request a call back, instead, use the communication methods listed below.



GMS Assist: Visit [GMSassist.com](https://www.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.



Phone: Call us at **(800) 795-3226** Monday through Thursday to speak with a live representative.



Keeping your potassium in balance

What is potassium?

Potassium is a nutrient your body needs for your nerves and muscles (including your heart) to work the way they should. Having **too much potassium** (hyperkalemia) can be **dangerous**, and cause:

- **Heart problems**, including a heart attack
- **Trouble breathing**
- **Inability to move your muscles**

What causes high potassium or hyperkalemia?



Kidney disease

If you have kidney disease, your kidneys may not filter out extra potassium, which can build up in your body.



Foods and drinks that are high in potassium

Avocados, potatoes, tomatoes, many juices, bananas, and many other foods.



Certain medicines

Some medicines make your potassium go up, including **RAAS inhibitors** (a blood pressure medicine that protects your heart). ACE inhibitors and ARBs are common RAAS inhibitors.

Keeping your potassium in balance for life

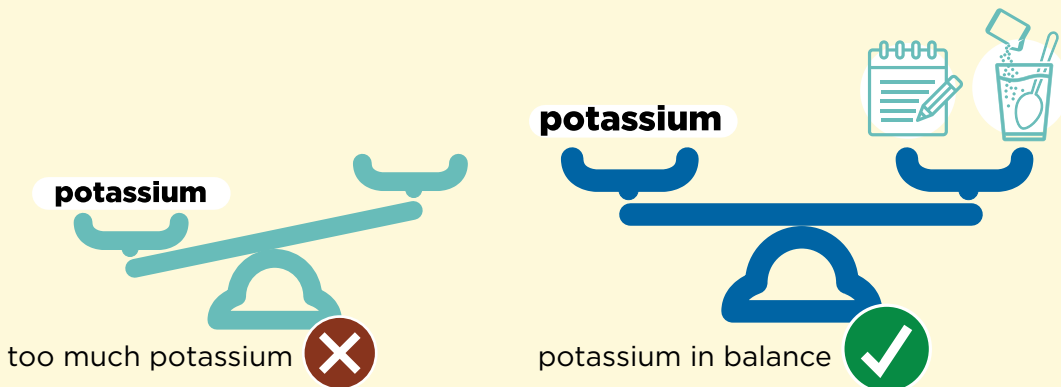


Track what you eat and drink so you do not take in too much potassium.

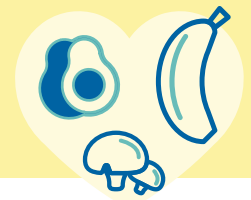


Take medicines called potassium binders.

These keep your body from absorbing potassium in your food or drinks.



- **Potassium binders** can help you get the benefits of RAAS inhibitors without raising your potassium levels.
- Binders can also give you the freedom to eat more nutritious, potassium-rich foods that are **good for your heart**.



For more information and free resources to help control your potassium, visit [KidneyFund.org/BeyondBananas](https://www.kidneyfund.org/BeyondBananas).

AKF staff spotlight



Name: Lianna Chase

Hometown: Richmond, VA

What do you do at AKF? I am the director of special events. I have one of the best jobs at AKF (although I am a little biased!) My job is to work with our senior director of special events to manage all AKF events like

The Hope Affair, A Pairing for Prevention: Boston, and the New York Golf Classic. I also manage both of our pediatric programs—Calendar Kids Art Contest and AKF's National Virtual Camp for kids with kidney disease.

What is your personal connection to kidney disease? When I first began working at AKF, I didn't think I had any personal connections to kidney disease. As many of us know, this disease affects so many and it was only a matter of time before my family and friends were able to help me make the connections! My uncle has celebrated many years living with a kidney transplant. Recently, one of my best

friends from childhood was diagnosed with kidney failure and began dialysis. I am so grateful for the resources AKF provides and the knowledge I have gained from my time here to be able to better understand their journeys with kidney disease.

Why are you passionate about fighting kidney disease? As a part of my job, I get to interact with kids and their families who are living with kidney disease. Getting to share in the highs and lows of their journey and see their hopes for the future inspires me to keep fighting for the best for kidney patients everywhere.

What is the best part of your job? The people I work with! Whether it is AKF staff, community members fundraising for kidney disease, or the campers that join our monthly zooms, AKF is truly all about the people. They each bring such great passion, skills, and joy to the work I get to do.

What are your favorite hobbies outside of work? I am (very slowly) learning how to golf—although putt putt may be where my skill set taps out. I also enjoy exploring new restaurants around Baltimore and hanging out with my dog, Abby!

Ask for donations for your birthday · Celebrate your transplant anniversary · Share your story · Host an online fundraiser

DIGNITY

QUALITY OF LIFE

HOPE

GIVE IT BACK

Take action. You can support AKF anywhere, anytime and join a community united by a bold vision: a world without kidney disease. Visit KidneyNation.org and start fundraising for AKF today!

KidneyNation.org

 American Kidney Fund[®]
KidneyNation

Help patients get access to lifesaving treatments · Help kids with kidney disease go to summer camp · Fund innovative research

Kidney Kitchen®

A pot pie is the ultimate comfort food. This unique version is loaded with tender veggies, herbs and creamy ricotta cheese, all wrapped up in a homemade crust, for a satisfying and hearty meal.



Vegetable Pot Pie

Makes: 8 Servings



Prep time: 45 min

Cook time: 80 min

Recipe contributed by
FamilyCook Productions



Cooking Tip: If you do not have a rolling pin, you can use any empty bottle you have at home to flatten the dough! Be sure to wash the bottle and remove any labels that might get in the way.

Nutrition facts

(1 serving = 1 wedge of pie)

Calories = 387
Carbohydrates = 29 g
Sugar = 4 g
Fiber = 3 g
Calcium = 158 mg
Fat = 26 g
Saturated Fat = 13 g
Trans Fat = 1 g
Protein = 12 g
Phosphorus = 201 mg
Cholesterol = 152 mg
Sodium = 145 mg
Potassium = 560 mg

Ingredients for Pie Crust:

1 $\frac{3}{4}$ cups unbleached flour
1 pinch sea salt

10 tablespoons unsalted butter,
cut into small pieces

$\frac{1}{4}$ cup ice water

Ingredients for Filling:

2 tablespoons olive oil
 $\frac{1}{2}$ pound (227 grams) spinach
leaves, rinsed, stems removed
and chopped
2 medium (121 grams) carrots,
diced
1 stalk (50 grams) celery, diced

1 medium (196 grams) yellow
squash, diced
8 ounces (227 grams) mushrooms,
wiped, cleaned and thinly sliced
4 eggs
 $\frac{3}{4}$ pound ricotta cheese
6 tablespoons dill, chopped
 $\frac{1}{4}$ cup basil, chopped

$\frac{1}{4}$ cup parsley, chopped
 $\frac{1}{2}$ teaspoon nutmeg, ground
1 pinch sea salt
 $\frac{1}{2}$ teaspoon black pepper, ground
2 tablespoons lemon juice
1 teaspoon lemon zest
 $\frac{1}{4}$ cup parmesan cheese, grated
2 teaspoons water

Special Equipment:

Rolling Pin

2-quart baking dish

Directions for Pie Crust:

1. Preheat oven to 375°F.
2. Combine flour and salt in a medium bowl.
3. Work the butter into the flour using a pastry cutter, a fork or your fingertips, until the mixture resembles coarse pea-sized pieces.
4. Drizzle in the cold water, one tablespoon at a time. Mix with your hands until a dough is formed.
5. Transfer the dough to a floured work surface. Knead until the dough forms a ball. Cover and refrigerate while preparing the filling.

Directions for Pie Filling and Assembly:

1. Heat 1 tablespoon of olive oil in a large skillet over low heat.
2. Add the spinach and cook, uncovered, until the liquid evaporates and the spinach is dry, about 10 minutes. Transfer to a bowl.
3. Heat the remaining 1 tablespoon of olive oil in the same skillet over medium heat. Add the carrots, celery, yellow squash and mushrooms, and sauté until the veggies are slightly tender, about 10 minutes.
4. Add the veggies to the bowl of cooked spinach and set aside.
5. Combine 3 eggs, ricotta, half the dill, the basil, parsley, nutmeg, salt, pepper, lemon juice and zest and parmesan in a large mixing bowl. Mix thoroughly.
6. Divide the pie dough in half. Roll out half the pie crust on a lightly floured surface. Drape evenly over the bottom of a deep 2-quart baking dish.
7. Spread half the ricotta mixture onto the bottom crust.
8. Spread the vegetables evenly over the ricotta mixture and sprinkle with remaining dill. Cover the vegetables with the remaining ricotta mixture.
9. Beat the remaining egg with 2 teaspoons of water in a small bowl and brush the edge of the pastry with egg wash.
10. Roll out the remaining dough half and drape evenly over the baking dish to cover the filling. Crimp the edges together.
11. Cut steam vents in the top of the pastry and brush the entire pie with egg wash.
12. Bake for about 1 hour, until golden brown.
13. Divide pie into 8 wedges and serve immediately.



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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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