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AKF Ambassadors

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AKF in ACTION

Fighting kidney disease and helping people live healthier lives.


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Become APOL1 Aware in honor of the first annual APOL1-Mediated Kidney Disease (AMKD) Awareness Day

On April 30, 2024, the nation's first AMKD Awareness Day will be held to spread awareness of APOL1-mediated kidney disease (AMKD), a group of kidney diseases associated with variants (mutations) in the apolipoprotein L1 (APOL1) gene and linked to an increased risk for rapidly progressing kidney disease in people of Western and Central African descent.

Everyone has two copies of the APOL1 gene, but people who have Western and Central African ancestry, including people who identify as Black, African American, Afro-Caribbean and/or Latina/Latino, are at an increased risk of having a mutation in one or both of the genes. People with two mutations are at higher risk of developing genetic forms of kidney disease such as focal segmental glomerulosclerosis (FSGS). It is estimated that 13% of Black Americans have two mutations of the APOL1 gene, and these individuals have a 1 in 5 chance of developing kidney disease.

The only way to know if you have the APOL1 gene variants is to have a genetic test. AKF has developed a guide to help inform people about genetic testing for APOL1, with information about insurance coverage and free testing for eligible patients. The guide, along with a number of other educational resources about AMKD, are available at KidneyFund.org/APOL1.

Congresswoman Stacey Plaskett of the U.S. Virgin Islands will be introducing a resolution to make the last Tuesday of April APOL1-Mediated Kidney Disease (AMKD) Awareness Day to encourage Americans to become better informed about kidney disease, and AMKD specifically, and to spur people from or with ancestry from Western and Central Africa to talk to their doctor about genetic testing for APOL1 gene mutations.

AKF will be hosting an event on Capitol Hill on April 9 to share information with congressional staff, members of Congress and the public and will provide resources and ways to engage and raise awareness of the important connection between APOL1 gene variants and kidney disease in the weeks ahead of AMKD Awareness Day on April 30.

For updates and more information on AMKD Day, visit KidneyFund.org/APOL1aware.

Support for AMKD Awareness Day is provided by



Working together and sharing our stories, we can help raise much-needed awareness about APOL1's connection to kidney disease and how where we come from may impact our kidney health. If you have an AMKD connection, share it with your family and friends. You can also share your story with AKF by recording a video at bit.ly/AMKDStoryShare. For more information on APOL1, visit KidneyFund.org/APOL1aware.

Kidney transplant voucher program 101

A kidney transplant can increase the chances of living a longer, healthier life, yet many people may not know about a transplant program that may shorten the wait time for a kidney. The National Kidney Registry (NKR)'s transplant voucher program allows living kidney donors to receive a voucher for their kidney. That voucher can then later be exchanged by a person of the donor's choosing so that person can receive a kidney. Then, both the donor and the voucher holder receive priority status on NKR's transplant wait list if/when they need a kidney. The donor may choose to use the voucher program because they may not be a match for the person they want to donate to, or they may be donating to a stranger. In either case, the best part is that vouchers don't expire.

There are two types of vouchers available: the standard and the family voucher. The standard voucher gives one voucher to a person the donor knows needs a kidney soon—usually within the next 12 months. The family voucher allows the donor to name multiple people who could someday use the voucher. Even though it is called a "family" voucher, these individuals do not need to be biologically related to the donor.

Here are some advantages of using NKR's transplant voucher program to get a kidney:

- **A shorter wait time for a kidney.** Receiving an organ from a living donor reduces your wait time. There are more than 90,000 people waiting for a kidney in the U.S. right now, and unfortunately, wait times for a deceased kidney can be years. If you find a living donor, you may only have to wait a matter of months.
- **Your donor gets priority.** Many potential living donors worry that they may need a kidney someday, but if they donate through the National Kidney Registry, they get prioritization for the living donor pool. This means the donor would not need to search for a living donor

themselves and instead would be offered a living donor, reducing their wait time.

- **Get the benefits of receiving a kidney from a living donor.** People who receive kidneys from living donors often have better post-transplant outcomes, including less chance of rejection and the kidney lasting longer.
- **Split up you and your donor's surgery/recovery.** If you and your donor undergo a traditional transplant surgery, you both will be having surgery and recovering at the same time. The voucher program allows the surgeries and recovery periods to happen at different times, which may be more convenient for the two of you.
- **Potentially get a kidney that is a better match for you.** If you have someone who would like to donate to you but is either not compatible or not the best possible match, they can still donate their kidney, and you would receive the voucher and get a better-matched kidney.
- **Your donor will qualify for Donor Shield protection.** Anyone who donates through NKR's transplant voucher program qualifies for their Donor Shield protections program (visit bit.ly/DonorShieldProtection for more information), which provides financial, logistical and legal support to help protect living kidney and liver donors.

For more information about the voucher program and finding a living kidney donor, visit bit.ly/KidneyVoucherInfo or scan this QR code:



Get assistance through AKF's Community Resource Finder

Using AKF's new Community Resource Finder—powered by findhelp—you can get assistance with paying your bills, accessing health care, getting emergency aid, finding support groups and more.

For more information about our Community Resource Finder, visit bit.ly/CommunityResourceFinder. To use the findhelp tool, visit bit.ly/findhelptool.



People who wish to receive a David Atkins grant must meet these qualifications:

- Be a living kidney donor who donated on or after Jan. 1, 2023
- Recipient's evaluation and/or surgery took place at a Massachusetts hospital
- Donor must permanently reside in the U.S. or its territories (i.e., donor does not have to live in Massachusetts)
- Donor incurred out-of-pocket expenses not covered by insurance

Note: the financial information of the donor or recipient is not required or considered when the Fund evaluates applicants for program eligibility.

For questions regarding the David Atkins Living Donor Assistance Fund, please reach out to livingdonor@kidneyfund.org.

For more information or to apply for a grant, visit kidneyfund.org/livingdonor or use the QR code below.

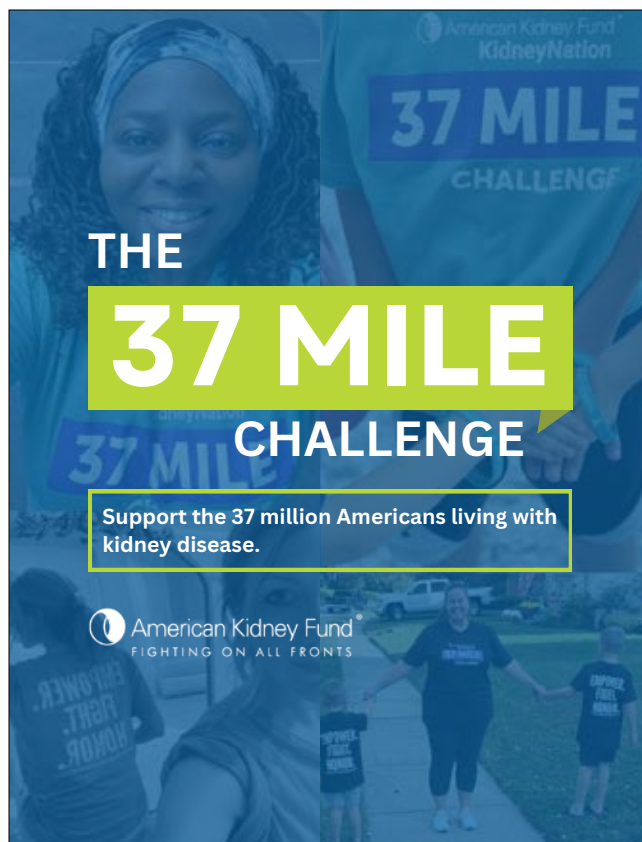
To learn more about The David Atkins Living Donor Assistance Fund, scan this QR code:



The David Atkins Living Donor Assistance Fund is here to help

AKF's David Atkins Living Donor Assistance Fund was founded by Matt Glazier and Julia Pepe, who named the Fund after Matt's kidney donor David selflessly gave him a second chance at a healthy life in 2021. The goal of the fund is to increase access to living kidney donations in Massachusetts by reimbursing the out-of-pocket costs to people who are saving a life by being living kidney donors.

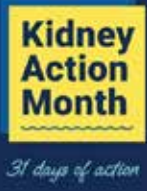
The Fund provides one lifetime grant of up to \$2,500 per donor, which can be used to cover childcare expenses, in addition to other out-of-pocket costs.



JOIN US FOR OUR NEXT 37 MILE CHALLENGE

Set health goals for 2024 and learn more about the AKF 37 Mile Challenge at www.kidneynation.org

Run or walk 37 miles in May to raise awareness and donations that will support kidney patients across the U.S. Challenge yourself to stay active, while helping us bring kidney patients the education, resources and treatments they need to manage their disease.



lack of general knowledge about the condition. This week informed people about the magnitude and impact of kidney disease, myths and misconceptions, the link between diabetes and high blood pressure and how to talk to a doctor about the condition. People also had an opportunity to take a quiz to test their knowledge about kidney disease.

Week 2 (March 11–15): It's your life! Managing your kidney disease. This week provided information on the five different stages of kidney disease, home dialysis options, maintaining a kidney-friendly eating plan, getting a transplant, clinical trials and other topics related to living with kidney disease.

Week 3 (March 18–22): Kidney Action Week (KAW). AKF held its fifth annual Kidney Action Week, a week-long virtual event dedicated to educating patients, caregivers and doctors on all things related to kidney health, including dialysis, kidney disease prevention, kidney-friendly eating, transplantation and innovations in kidney disease. In addition to taking part in the various live informational sessions, participants were able to connect with experts and health resources to help them live their best life. Visit AKF's YouTube channel at youtube.com/@kidneyfund/featured in the coming weeks to watch video replays of the KAW sessions.

Week 4 (March 25–29): Pay it forward: share or support. This week is all about taking action to support kidney patients and help fight kidney disease. AKF will be sharing resources on fundraising and becoming a Partner for Change and will be encouraging donors to record and share their own videos about why they support AKF.

To learn more about Kidney Month, visit AKF's Kidney Month hub at KidneyFund.org/kidney-month.

All about Kidney Month

March is Kidney Month, which this year has focused on equipping and empowering people to take action in the fight against kidney disease. Kidney Month is an opportunity for AKF to deliver tools and resources people need to prioritize their kidney health. Each week of March has had a different theme and goal(s):

Week 1 (March 4–8): Knowledge is power: what you need to know about kidney disease. Despite the fact that kidney disease affects 37 million Americans, there is a shocking



Federal legislation is needed to protect living organ donors from discrimination

AKF is continuing its work to help encourage living organ donation through its advocacy efforts. A 2014 study found that up to 25% of living donors had difficulty securing life insurance, and with dialysis patients reporting that potential living donors have passed on giving the gift of life because of the fear of being unable to obtain life insurance, ensuring protections for living donors is a priority for AKF. To date, 32 states have enacted laws that would prohibit life insurers from discriminating against living organ donors; however, a federal statute would cover every American.

The Living Donor Protection Act (H.R. 2923/S. 1384) would ensure that all Americans who have chosen to become an organ donor would have access to life, disability and long-term care insurance. The American Council of Life Insurers (ACLI) and the National Council of Insurance Legislators (NCOIL) have joined patient groups and health care providers in support of the federal legislation, in part because studies show that living donors live just as long as anybody else. Most importantly, donating an organ is one of the most selfless actions a person can take; no one should face discrimination because of it. To ask your senators and representative to cosponsor this important legislation, please visit KidneyFund.org/act.

AKF staff spotlight



Name: Shannon Teixeira

Hometown: Silver Spring, Maryland

What do you do at AKF? I am the director of information technology and platform solutions. I lead and manage the information technology (IT) function within

AKF and am responsible for developing and executing IT strategies, managing IT resources and ensuring the security and reliability of our technology infrastructure.

Why are you passionate about fighting kidney disease?

As an employee of the American Kidney Fund, I'm deeply passionate about fighting kidney disease because I've witnessed its profound impact on individuals and their families. Our commitment to supporting kidney research and education, providing grants, advocating for patients

and enabling transplant patients to live better lives is not just a job for me; it's a mission that drives me daily. Kidney disease affects millions of people worldwide, and its physical, emotional and financial toll is substantial. I'm passionate about this cause because I believe in the power of research and education to make a difference.

What is the best part of your job? The best part of my role is the opportunity to directly and meaningfully impact our mission. Every day, I can leverage technology to advance our cause. I get to work closely with a team of dedicated professionals who share a common goal and a deep commitment to improving the lives of individuals affected by kidney disease.

What are your favorite hobbies outside of work? Outside of work, I have a strong passion for the automotive world and car culture, which I inherited from my family of mechanics. This lifelong interest has brought me immense joy and has become one of my favorite hobbies. I find great satisfaction in various automotive-related activities and events, and I enjoy sharing these experiences with my son and close friends.

Kidney Kitchen®

These savory tarts are vegetarian friendly. Using prepared pastry dough, this appetizer saves you time in the kitchen that you can spend enjoying with your loved ones.



Ingredients:

- | | |
|--------------------------------------------|----------------------------------------------------------------|
| 2 medium carrots, peeled and thinly sliced | 1 clove garlic, crushed |
| 2 medium leeks, trimmed and thinly sliced | 2 tablespoons fresh or dried mixed herbs (oregano, sage, etc.) |
| 1 tablespoon olive oil | 14 ounces puff pastry dough |
| | 6 ounces soft goat cheese |

Carrot Leek and Goat Cheese Tarts

Makes: 8 Servings

Serving size: 1 tart



Prep time: 15 min

Cook time: 40 min

Recipe contributed by Satellite Healthcare



Cooking Tip:

Tarts can be baked ahead of time, then reheated in an oven at 375 degrees Fahrenheit for about 10 minutes.

Directions:

1. Preheat oven to 400 degrees Fahrenheit.
2. In a large saucepan, boil the carrots in water for 5 minutes.
3. Add the leeks and boil for 5 more minutes.
4. Drain well, then return to pan. Stir in olive oil, garlic and mixed herbs. Let cool.
5. Cut the pastry dough into eight squares and place on a parchment-lined baking sheet. Divide the vegetable mixture into eight equal portions and spread onto each pastry square, leaving a ¼-inch border around the edge. Dot the goat cheese on top of the vegetables. Bake 30 minutes or until pastry is golden brown.
6. Cool and serve.

Nutrition facts

(1 serving = 1 tart)

Calories = 169
Carbohydrates = 21 g
Sugar = 1 g

Fiber = 1 g
Calcium = 88 mg
Fat = 8 g

Saturated Fat = 4 g
Trans Fat = 0 g
Protein = 5 g
Phosphorus = 47 mg

Cholesterol = 6 mg
Sodium = 274 mg
Potassium = 118 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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