



Jessie Ward, Beaver, WV
AKF Ambassador

FALL 2024 | VOL. 9.3

AKF in ACTION

Fighting kidney disease and helping people live healthier lives.

3 New guidelines from AKF will help people with chronic kidney disease manage high potassium

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Inside the 2024 Transplant Games with AKF Ambassadors

From July 5-11, thousands journeyed to Birmingham, Alabama for the 2024 Transplant Games. Hosted in a different city every two years, the Transplant Games is a six-day event that brings together people who have received eye, tissue or organ transplants as well as living donors, donor families, caregivers and health care professionals to compete in over 20 activities ranging from a 5K run (or walk) to basketball to ballroom dancing to Texas Hold ‘Em poker.

Three of the people in attendance were AKF Ambassadors Chris Bryant, Pesh Patel and Iris Resto.

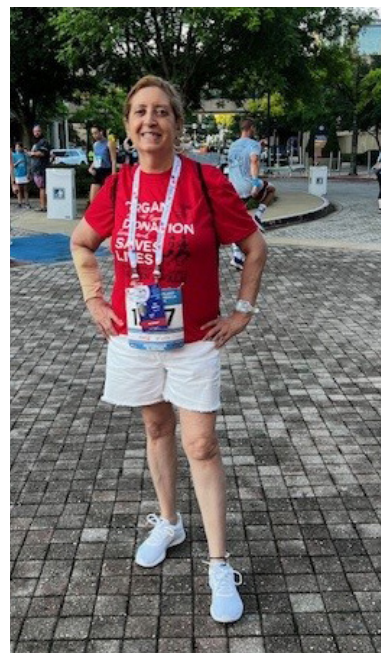
Iris just celebrated 17 years with her kidney transplant, which she needed after polycystic kidney disease (PKD) caused her kidneys to fail. “I was scared to attend because I thought you had to be really good at these sports. I am not athletic at all. But a few of my friends had gone and

they suggested that I should go [and] that I would really enjoy them. I finally decided I should go. I really enjoyed myself. It was a great feeling spending time with so many people that have had transplants.”

Iris participated in the 5K as well as the cornhole, darts and bowling events. She earned the bronze medal in bowling and placed fourth in cornhole.

Chris was attending the Transplant Games for the first time, although he plans to attend more. Like Iris, he competed in the cornhole event and brought home a bronze medal (in the trivia event) for the Liberty Team – whose members are from Connecticut, New Jersey and New York. “My team cheered and was very welcoming,” Chris said, who is living with his second pancreas/kidney transplant. “The stories I

Continued on next page. ➡





AKF teams up with Sunni Lee to help educate and empower people to know the cause of their kidney disease

Olympic gold medalist Sunni Lee and AKF announced their partnership over the summer for AKF's Know Your Kidneys™, a comprehensive program that provides a roadmap to better kidney health. Lee will discuss her kidney disease experience, shed light on unknown causes of kidney disease and share resources that can help those seeking a diagnosis.

This summer, at the 2024 Olympic Games in Paris, Lee won gold in the women's artistic team all-around event, as well as two bronze medals in the women's artistic individual all-around and the women's uneven bars. At the 2020 Olympic Games in Tokyo, she won gold in the individual all-around event as well as a silver medal and bronze medal in the women's uneven bars. Lee disclosed in 2023 that she had been diagnosed with kidney disease of an unknown origin. As a result, Lee took a break from gymnastics to focus on her health but was later cleared by her health care team to return to competition and received widespread praise for her return.

Up to 15% of people with kidney disease do not know the cause of their disease. The Know Your Cause pathway, part of Know Your Kidneys, offers information about testing options, genetic counseling and 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, which is critical to ensure the most effective treatment plan.

To read more about AKF's partnership with Lee, visit bit.ly/SunniPartnership. Visit KidneyFund.org/know-your-kidneys/cause or use the QR code below to explore AKF's Know Your Cause pathway.

To explore AKF's Know Your Cause pathway, scan this QR code:



Inside the 2024 Transplant Games, cont.

← Continues from previous page

heard blew me away. This experience will always stay with me."

This was also Pesh's first time at the Transplant Games, although he chose to be a spectator rather than a competitor. His favorite part of the Transplant Games was "realizing that everyone there was family."

"From the members of Team Louisiana to the conversations I had at the Westin bar at the end of each day, we all have a shared experience and support each other through our individual journeys," said Pesh, who is

back on the kidney transplant waitlist as he experienced kidney rejection in February 2021.

Chris agreed, sharing that the best part for him was "hearing the journeys of the participants. From the donors, donor families, recipients and those still waiting, it gave me a feeling of community."

"These Transplant Games are a reminder that you are not alone in this journey," said Chris. "Lean on your friends, family, and health care team — they are all here to support you."

We look forward to seeing Chris, Pesh and Iris — and the thousands of others who have experienced the lifechanging impact of organ transplants — at the 2026 Transplant Games.

Visit bit.ly/AKFTransplantGames to read the full recap of the Transplant Games

New guidelines from AKF will help people with chronic kidney disease manage high potassium

Over the summer, AKF launched patient-focused guidelines to help people with chronic kidney disease (CKD) manage and treat hyperkalemia, also known as high potassium. Kidney disease is the most common cause of hyperkalemia, a serious and potentially life-threatening condition that can cause an irregular heartbeat or a heart attack.

People with CKD are at an increased risk of developing hyperkalemia because their kidneys do not work as well as they should to remove extra potassium in the blood, leading to elevated levels of potassium in the body. Not treating high potassium can cause severe heart problems, which makes careful management of high potassium critical.

It is important for people with CKD to meet with their health care provider to develop a personalized plan to manage and treat high potassium based on their health situation. AKF's guidelines include tips to help people follow the plan created by their provider, along with information on checking potassium numbers, symptoms of hyperkalemia, medicines that can help manage potassium numbers and foods to eat and avoid.

AKF conducted focus groups with both patients and professionals to help inform the development of the guidelines and worked with medical experts on the evidence-based, health literate content. Focus group participants, consisting of people with hyperkalemia and people in the general kidney patient population, were asked to share their awareness of hyperkalemia and their knowledge of how to manage it.

To view the hyperkalemia guidelines, visit bit.ly/HyperkalemiaGuide or use the QR code below. The guidelines are also available in Spanish at bit.ly/HyperkalemiaSpanish. For more resources on managing hyperkalemia, visit AKF's Beyond Bananas campaign website at bit.ly/BeyondBananaHyperkalemia.

The hyperkalemia guidelines were developed with support from AstraZeneca.

For more resources on managing hyperkalemia, scan this QR code:



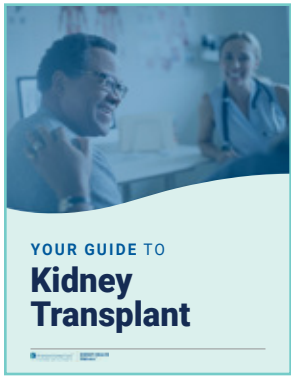
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DIALYSIS AT HOME

A virtual kidney community event

REGISTER at kidneyfund.org/DAH2024





Have questions about the transplant process? Check out our new resource

For many people, the process of getting a kidney transplant is confusing, overwhelming and complicated. People oftentimes don't know the right questions to ask, where

to get the answers or which answers are correct.

To assist with the transplant process, AKF has designed a transplant resource – available in English and in Spanish – to provide those considering a transplant and their loved ones with a comprehensive overview of the transplant process. In this guide, patients will find useful information, including:

- Transplant options
- Benefits and risks

- Transplant centers
- Eligibility requirements
- Evaluation process
- Expectations for caregivers
- Kidney donation

Visit bit.ly/GuidetoTransplant to view the toolkit in English and bit.ly/GuidetoTransplantSpanish to view it in Spanish.

Learn more about AKF's efforts to remove barriers to kidney transplants at KidneyHealthforAll.org.

To download the guide, scan this QR code:



English



Spanish



Federal legislation is needed to eliminate racial and ethnic health inequities and address kidney disease research, surveillance, prevention and treatment

AKF is pleased to support the Health Equity and Accountability Act (HEAA), which was introduced by Sen. Mazie Hirono and Reps. Barbara Lee and Judy Chu.

While kidney disease affects people of all genders, races, ethnicities and backgrounds, Black Americans, Hispanic Americans, Native Americans and Asian Americans are at a higher risk of developing kidney failure than white Americans are. Specifically, Black Americans are four times more likely, Hispanic Americans/Latinos and Native Americans are about two times more likely and Asian Americans are 1.6 times more likely.

HEAA would make a number of crucial investments in the kidney health of all Americans and improve kidney health equity by:

- Expanding ongoing research into kidney transplants in minority populations

- Calling for a report to examine racial disparities in the use of home dialysis and examine coverage for, and use of, home dialysis in rural communities
- Expanding the Medicare Annual Wellness Benefit to include kidney disease screening, which is crucial for early detection and prevention of late-stage kidney disease
- Supporting research into the environmental and occupational causes and biological mechanisms that contribute to kidney disease

To learn more about HEAA, visit bit.ly/HEAARelease.

To learn more about HEAA, scan this QR code:



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](https://www.velphorovoices.com).

Scan the code with your cell phone camera

INDICATION

Velphoro[®] (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.
- 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](https://www.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/ 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.

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

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AKF launches new living donor assistance program

With more than 90,000 people in the U.S. on the kidney transplant waiting list, the need for living kidney donors is urgent. As part of AKF's efforts to reduce barriers and financial hardships for people who wish to donate a kidney, the American Kidney Fund Living Donor Assistance Fund, sponsored by the Sievers Family Charitable Fund, will open on Oct. 1.

The fund, which will support people who are donating a kidney to a recipient in the Greater Washington Metropolitan Area (DMV), will help ensure that the costs associated with living organ donation not covered by insurance are not an obstacle to donating a kidney to someone in need.

Living donors of kidney transplants occurring at DMV hospitals may apply for one lifetime grant of up to \$2,500, which can be used to reimburse transportation costs, childcare expenses and other out-of-pocket costs.

Living donors seeking a grant must meet these qualifications:

1. Be a living kidney donor on or after Oct. 1, 2024.
2. The recipient's evaluation and/or surgery must take place at one of the following DMV hospitals:
 - George Washington University Hospital, Washington, D.C.
 - Medstar Georgetown Transplant Institute, Washington, D.C.
 - Children's National Medical Center, Washington, D.C.

- Johns Hopkins Hospital, Baltimore, MD
 - University of Maryland Medical System, Baltimore, MD
 - Inova Fairfax Hospital, Falls Church, VA
3. Donor must permanently reside in the U.S. or its territories but does not have to live in the DMV.

Program Requirements

1. Reimbursement is available at the federal daily reimbursement rate for up to 10 days for donor related out-of-pocket expenses for travel and childcare costs not covered by insurance or any other program. The maximum grant is \$2,500.
2. Currently, financial information of the donor or transplant recipient is not required or considered for evaluation of applicants for program eligibility.
3. Receipts are required for travel expenses (plane/train fare, etc.).
4. A maximum of 10 days may be requested at the daily rate for these expenses.
5. Verification is required by the transplant hospital.
6. The application may be submitted by either the donor or the transplant hospital.

In 2023, AKF established the David Atkins Fund with a similar aim, supporting people who make the gift of life to kidney patients in Massachusetts; that program was expanded earlier this year to include people donating a kidney to a patient in the New York City area.

For more information, please visit

[KidneyFund.org/livingdonor](https://www.kidneyfund.org/livingdonor) to apply, beginning on Oct. 1. Questions may be emailed to livingdonor@kidneyfund.org on or after that date.



How to contact us

If you have specific questions relating to AKF's assistance programs or need help with AKF's Grants Management System (GMS), please contact AKF's Patient Support department:

Phone: From 11 a.m. to 2:30 p.m. EST Monday–Thursday, call **(800) 795-3226** to speak with a live representative. Please note that voicemails are not accepted or responded to. Please do not leave messages in other departments.

GMS Assist: Visit [GMSassist.com](https://www.gmsassist.com) to make a 30-minute phone appointment at a time that is convenient for you. Messages, voicemails, or emails sent to other departments

or to Patient Support requesting a call back will not be processed.

Through GMS: Please message us through your GMS user account at [gms.kidneyfund.org](https://www.gms.kidneyfund.org). Check the Learning Center and FAQ sections of your account for up-to-date information.

GMS Virtual Assistant: The Virtual Assistant, found at [gms.kidneyfund.org](https://www.gms.kidneyfund.org), answers FAQs and gives you the ability to add tickets for help 24 hours a day.

Visit [KidneyFund.org](https://www.kidneyfund.org) to learn more about AKF's patient financial assistance programs, or email us at registration@kidneyfund.org if you are having issues registering on GMS.



Toward a level playing field: How a change to race-based eGFR calculations is increasing access to transplant among Black patients

A policy change aimed at improving kidney transplant equity has so far shortened the waitlist time for a lifesaving organ for more than 14,000 Black patients. Two of those patients, Charlotta T. and Craig M., both diagnosed with kidney failure, shared their stories with us.

In July 2023, the Organ Procurement and Transplantation Network (OPTN) changed its policy to require that transplant centers use a race-neutral calculation to determine a transplant candidate's estimated glomerular filtration rate (eGFR). The policy requires transplant hospitals to use the same calculation for all kidney patients, instead of using a separate equation for Black patients, which historically put Black kidney patients at a disadvantage by overestimating their kidney function. This made the kidneys look healthier than they really were and led to Black patients waiting longer for kidney transplants.

Craig said he felt immensely grateful to learn he'd be benefiting from the change. Diagnosed with stage three kidney disease at age 29, Craig said that once he had to go on dialysis, the experience was very difficult for him, as it took a toll on his body, mind and spirit. So, when he found out in early November 2023 that he was being credited for four years on the waitlist because the race-inclusive

eGFR caused him to wait for longer than he should have had to wait, he was thrilled, as he had already been on the transplant waitlist for four years.

A couple of days later, Craig received a phone call that a kidney match had been found. He received his new kidney just before Thanksgiving, feeling deeply moved by the bittersweet situation. "I'm a recipient of [my donor's] sacrifice, so that was very touching," he said, referring to the fact that his donor had sadly been pronounced brain dead at just 35 years old.

Charlotta suffered from gradually declining kidney function for years. Like Craig, she was thrilled when her transplant coordinator told her that she would benefit from the policy update – only for her, the benefit was being put on the transplant waitlist in the first place. According to the coordinator, Charlotta should have been placed on the waitlist years earlier. She received nine years of credit from Yale New Haven Transplant Center and eight years from Hartford HealthCare.

Just three and a half weeks after getting on the waitlist, Charlotta received her first phone call with an offer for a new kidney. Although that offer didn't pan out, Charlotta got another offer a couple of weeks later that she was able to accept, and she received her new kidney in September 2023 at Hartford HealthCare.

Getting a transplant marked a new beginning for Charlotta and Craig – a beginning that may not have happened for several more years had it not been for the OPTN policy update. "[This change] gives people opportunity," Charlotta said. "There's no way I would have gone on the transplant list at the top of the list and been there for only three and a half weeks had it not been for all the research and the work that went into the process of changing a bad system."

Craig said he thinks often about the people who are no longer with us because they had to wait longer than they should have to get a transplant. "They could have received a transplant a lot sooner, [but instead] they passed away because of this inequality," said Craig. "I'm very grateful for the change and for the individuals who led the charge and said, 'we have to change this.' I don't know the names of those individuals, but I believe I owe them something, so my fight and my mission is to educate and inspire and continue to share my story with others."

Visit bit.ly/eGFRChangeBlog to read the full blog post about the OPTN policy change.

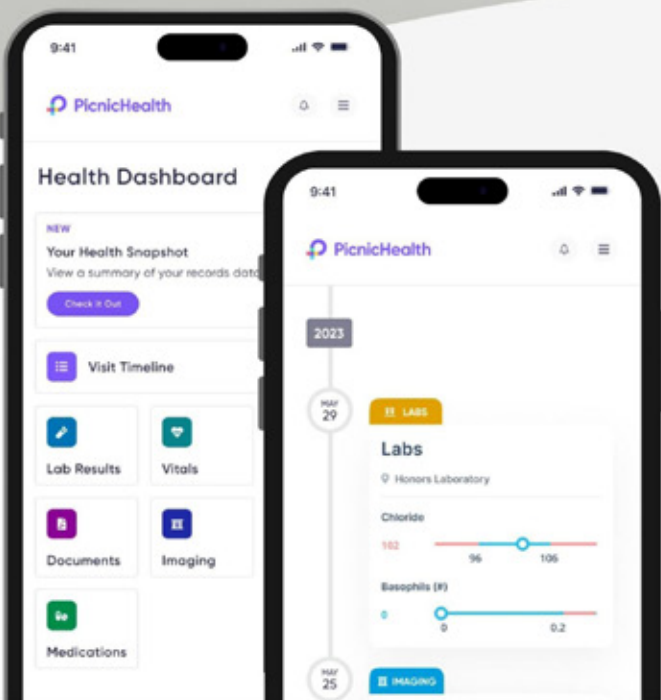
For more information about kidney transplants, visit bit.ly/TransplantGuides.

Visit bit.ly/OPTNPolicyChange for more information about OPTN's policy change to a race neutral eGFR calculation.



Your story matters for IgAN research

Help propel research and optimize care for those living with IgA Nephropathy.



In this research, we are looking at data from medical records produced during your normal visits to the doctor. The goal is to better understand how patients across the US are being treated and why IgA Nephropathy looks different in different people.

After you sign up, and your eligibility is confirmed, you will also receive a free membership to PicnicHealth

Sign Up Today!

To enroll, call us at **(415) 801-0572** or visit us online at picnichealth.com/AKF

If you have been diagnosed with IgA Nephropathy via kidney biopsy and receive medical care in the U.S., you may be eligible.

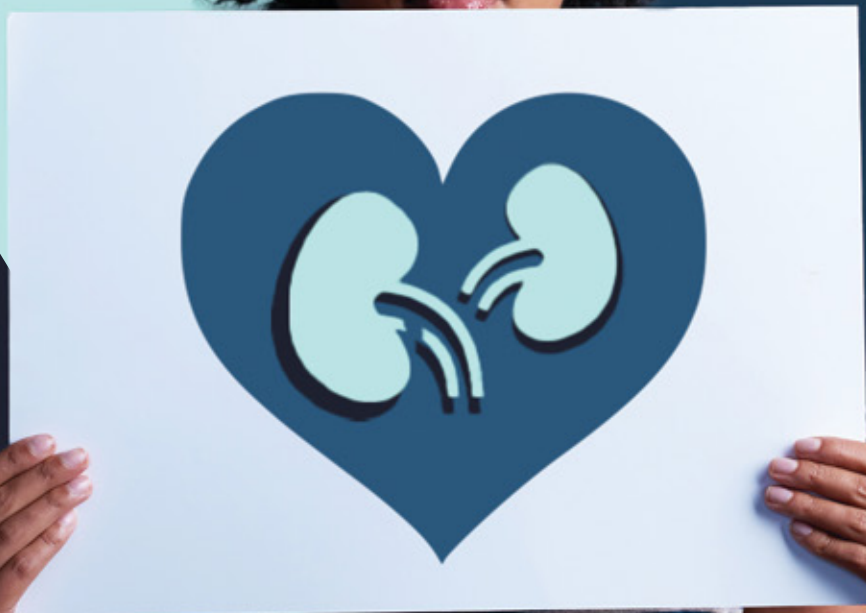


Manage high potassium long-term.

Get Your Hyperkalemia Guide today.
Visit [kidneyfund.org/hyperkalemia-guidelines](https://www.kidneyfund.org/hyperkalemia-guidelines)

beyond
bananas+

 American Kidney Fund®
FIGHTING ON ALL FRONTS



AKF staff spotlight



Name: Lauren Andracchio

Hometown: Rockville, Maryland

What do you do at AKF? I am the associate director of outreach and strategic partnerships. I work on a variety of projects, including Kidney Action Week, projects affiliated

with AKF's Health Equity Coalition and collaborations with various AKF partners. These projects entail working with renal professionals and patients to bring kidney education to the kidney community, with my particular focus being on kidney transplant education.

Why are you passionate about fighting kidney disease?

With kidney disease affecting one in seven American adults and about 90% of those with kidney disease not knowing they have it, there is so much work to be done to increase awareness and reduce the impact. These figures, along with each personal kidney disease story I hear, are part of my "why." As I've listened to kidney professionals talk

about medical progress made in this space, I get excited about the potential kidney disease landscape in the future. I am passionate about this work because I love fighting alongside advocates, health care providers and AKF staff as we shine light on the possibilities of a world without kidney disease.

What is the best part of your job? The best part of my job is working directly with people impacted by kidney disease. I've learned so much from them over the years—both about kidney disease and the human experience. Their ability to be vulnerable and share their stories with kidney disease for greater awareness is invaluable. As part of working with people living with kidney disease, I also have the great honor to hear about how AKF's programs and resources have impacted them personally, which is incredibly rewarding.

What are your favorite hobbies outside of work? In my spare time, I like to get outside with my family and find new adventures for my two kids (and a third on the way)! Hiking, running and spending time by the water are some of my favorite activities. I also love to bake—there's nothing like bringing joy to those you love through food.

Kidney Kitchen®



This and other recipes can be found at kitchen.kidneyfund.org.



Ingredients:

1 large egg	2 thick slices of brioche bread	1/8 teaspoon nutmeg, ground
1/4 cup milk, whole fat	1 teaspoon coconut oil	1 tablespoon maple syrup
1 teaspoon vanilla extract	1/2 medium-sized apple, fresh, unpeeled, sliced thinly	
1/2 teaspoon cinnamon, ground		

Special Equipment:

Medium non-stick skillet

Apple Pie French Toast

Makes: 1 Serving

Serving size: 2 slices French toast and apple topping



Prep time: 10 min
Cook time: 15 min

Recipe contributed by
Family Cook Productions

Nutrition facts

(1 serving = 2 slices of French toast and apple topping)

Calories = 283	Trans Fat = <1 g
Carbohydrates = 35 g	Protein = 8 g
Sugar = 16 g	Phosphorus = 120 mg
Fiber = 2 g	Cholesterol = 132 mg
Calcium = 81 mg	Sodium = 137 mg
Fat = 12 g	Potassium = 193 mg
Saturated Fat = 5 g	

Directions:

1. Whisk together the egg, milk, vanilla extract and 1/4 teaspoon of the cinnamon in a shallow dish.
2. Heat a non-stick skillet over medium-low heat.
3. Place 2 slices of bread in the batter; set for 10 to 15 seconds to absorb. Flip the bread over; set for 10 to 15 seconds more.
4. Add 1/2 teaspoon of the coconut oil to the pan, swirling to evenly coat the bottom of the pan.
5. Add soaked bread to the skillet; cook without moving until browned on bottom (about 4 to 5 minutes).
6. Flip the bread over and add remaining 1/2 teaspoon of coconut oil to the skillet. Cook until the second side is browned, about 4 to 5 minutes.
7. Heat a separate skillet over medium-low heat.
8. Add apple slices, nutmeg, maple syrup and remaining 1/4 teaspoon cinnamon.
9. Reduce heat to low. Stir constantly to avoid burning syrup, for 2 to 3 minutes, or until apples are cooked to desired softness.
10. Remove browned toasts from heat and place on a serving plate.
11. Cover toasts with cooked apples, drizzling with any remaining juices in the pan.

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[KidneyFund.org](https://www.kidneyfund.org)

AKF is fighting on all fronts as the nation's leading kidney nonprofit. Sign-up to receive our monthly e-newsletter to get the latest updates at [KidneyFund.org/sign-up](https://www.kidneyfund.org/sign-up).

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