



AKF in ACTION

### Fighting kidney disease and helping people live healthier lives.

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'Better than meeting red pandas,' says living kidney donor about donating her kidney to a stranger

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# **American Kidney Fund Financial Assistance Programs**

he American Kidney Fund (AKF) is well known for the Health Insurance Premium Program (HIPP), which offers low-income dialysis patients financial assistance in paying for their health insurance premiums. In addition to HIPP, AKF also offers a variety of other financial assistance programs to these dialysis patients and recent kidney transplant recipients. These programs include the Safety Net Program, the Safety Net Program for DC, MD, and VA Residents, the Disaster Relief Program and the Post-Transplant Testing Program.

The Safety Net Program can help with expenses such as transportation costs, mobility aids, medication co-pays, pharmacy needs and other health care expenses not covered by insurance. Assistance is provided in the form of a debit card or direct deposit. In most U.S. states and territories, the amount for SNP is \$100 per grant. For those in DC, Maryland and Virginia, this program offers up to \$250 thanks to a generous donation from the Robert I. Schattner Foundation.

When a natural disaster strikes a community, AKF opens its Disaster Relief Program to help dialysis and post-transplant patients replace lost medication and food, pay for temporary housing and transportation to treatment, or replace clothes and other essentials. In 2021, DRP provided \$480,500 to more than 2,300 people affected by natural disasters.

Our newest program, the Post-Transplant Testing Program, offers kidney transplant recipients assistance to cover innovative new blood tests that offer ongoing tracking of the health of a transplanted kidney to look for kidney injury or rejection without the need for a kidney biopsy. PTTP grants of up to \$1,200 a year are available for qualifying

patients who received their transplant within the last 10 years.

You can learn more about all our programs by going to **KidneyFund.org**, clicking on Menu, and selecting "Get assistance." To apply, go to Grants Management System (GMS) by clicking on the GMS login button on our website or go directly to **gms.KidneyFund.org**. Once you've registered, make sure to check out the Information tab for guides on how to submit grant requests and other useful information. If you have any questions or require assistance, please call 800.795.3226 or schedule a call-back appointment at **GMSassist.com**.

#### **Questions?**

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** 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.



**Phone:** Call us at **1.800.795.3226** from 11 a.m. to 3 p.m. ET Monday through Thursday to speak with a live representative. To protect your privacy, voicemails are not accepted.



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



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



# Important food safety tips for hurricane season

urricane season has started and to make sure you are prepared, the American Kidney Fund's Kidney Kitchen® collaborators, USDA's Food Safety and Inspection Service (FSIS) encourage you to consider making a "hurricane plan" for food safety.

Food safety is especially important for people living with kidney disease since your kidneys are not functioning properly. This means your immune system may be weakened and foodborne illnesses may be harder for you fight off, making your symptoms more severe. Knowing what to do in case of a hurricane emergency is key to ensuring you are prepared—and to protecting your health.

# In case of hurricane flooding

Depending on the severity of the storm, hurricanes can cause flooding or structural damage to your home or neighborhood. If you experience a flood, keep these food safety-related tips in mind:

- Do not eat any food that may have come in contact with flood water.
- Throw away any food that is not in a waterproof container if there is any chance it may have come in contact with flood water. Food containers that are not waterproof include those with screw-caps, snap lids, pull tops or crimped caps.
- Thoroughly wash metal pans, ceramic dishes, utensils (including can openers) with soap and water (hot water if available). Rinse and sanitize them by boiling in clean water or immersing them for 15 minutes in a solution of 1 tablespoon of unscented, liquid chlorine bleach per gallon of drinking water.

Another major concern for your food safety in a hurricane is losing power. Power is critical to ensuring perishable foods stay safe, because harmful bacteria can multiply to dangerous levels when temperatures are above 40°F.

## Before a hurricane power outage

If you know you may be affected by a hurricane or power outage due to severe weather, plan ahead and prepare by following these steps:

- Keep an appliance thermometer in both the refrigerator and freezer.
- Freeze refrigerated items that you may not need immediately, such as leftovers, milk, and fresh meat and poultry. This will keep them at a safe temperature longer.
- Have a large, insulated cooler and frozen gel packs or ice available.
   You can pour water into containers and freeze it to make ice.
- Find out where you can purchase dry ice and block ice. Fifty pounds of dry ice should keep an 18-cubic-foot freezer cold for two days. (Caution: Do not touch dry ice with bare hands or place it in direct contact with food.)
- Stock up on non-perishable items that do not need refrigeration for food safety.
- Place foods on higher shelves to lessen the chance of them being contaminated by flood water.

# During or after a hurricane power outage

During a power outage, keep in mind that the refrigerator will keep food safe for up to 4 hours. Also, a full freezer will hold the temperature for approximately 48 hours (24 hours if it is half full).

If the power does go out, keep these other important tips in mind:

Keep refrigerator and freezer doors closed.

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### Important food safety tips for hurricane season, cont.



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- If the power will be off for more than 4 hours, transfer food to a cooler and fill with ice or frozen gel packs. Make sure there is enough ice to keep food in the cooler at 40°F or below. Add more ice to the cooler as it begins to melt.
- Throw away perishable foods in the refrigerator after four hours, and perishable foods in the freezer after 24 hours if half full or 48 hours if the freezer is full.
- After a power outage, consult the chart in FSIS's "A Consumer's Guide to Food Safety: Severe Storms and Hurricanes" on the USDA FSIS website to determine what foods are safe to keep and which are not.

As a reminder, never taste food to determine its safety. When in doubt, throw it out!

Find more food safety tips specifically for those living with kidney disease on Kidney Kitchen and more tips about keeping food safe during severe storms and hurricanes on the USDA FSIS's website. You can also find AKF's infographic for preparing for a natural disaster, which also has great tips for people living with kidney disease like a 3-day emergency kidney-friendly food plan, in its resource library at KidneyFund.org/resources.

If you have additional severe weather or power outage food safety questions, you can also call the USDA Meat and Poultry Hotline at 1-888-MPHotline (1-888-674-6854), email MPHotline@usda.gov or chat live at ask.usda.gov from 10 a.m. to 6 p.m. ET, Monday through Friday.

### **AKF** staff spotlight



Kyndele Jane Rhudy

Hometown: Brandywine, Md.

What do you do at AKF? I am the Director of Corporate Engagement. I get to work with companies and build

meaningful relationships and raise funds for important programming and education.

What is your connection to kidney disease? My grandfather fought failing kidneys in his final year of life.

Why are you passionate about fighting kidney disease? Watching my family navigate my grandfather's health in his last years, I see the importance in kidney disease education for patients and their family/caregivers.

What is the best part of your job? The best part of my position is being able to watch and experience the impact of our work in the kidney community through the robust online community that has been built through our Kidney Action Week and 37 Mile Challenge. The community online is so positive and encouraging! It makes me happy to provide more for them.

What are your favorite hobbies outside of work? Outside of work I am a mom of two toddlers. My hobbies include playing with hot wheels, Barbies and watching lots of Disney films. I am also a Nationals fan as well as a self-proclaimed foodie and LOVE to explore different restaurants with my husband in my free time!





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

Visit 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





# AKF hosts an educational and inspiring Kidney Action Week

rom June 6-10, AKF held its third annual Kidney Action Week—a week-long, virtual event aiming to connect people with kidney disease, caregivers and healthcare providers in AKF's on-going efforts to bring patient-centered kidney-related education to the public. Kidney Action Week 2022 included 19 sessions and the new addition of 15 pre-recorded mini-sessions. Mini-session topics included cooking demonstrations, mental health discussions and even chair yoga!

Missed this year's Kidney Action Week? Don't worry! All sessions were recorded and can be viewed at your leisure at **KidneyActionWeek.org** or on AKF's YouTube channel. Here are a few sessions you may be interested in watching:

## Home Dialysis: What to Know and What to Ask

Home dialysis can provide people with kidney failure with more flexibility and better health outcomes. Despite its benefits, home dialysis usage in the United States is still low.

In this inspiring session, nephrologist Maria Camila Bermudez dispelled the myth that having too small of a home can disqualify you for home dialysis and shared different options for receiving supplies. AKF Ambassadors

John R.B. Bayton and Kyle Chang shared their individual journeys with kidney disease, as well as the ups and downs of home hemodialysis and peritoneal dialysis.

## **Kidney Transplant: Navigating the Waitlist**

When a person is considered for a kidney transplant, an evaluation team takes into account their physical and mental health, as well as their finances. Dr. Velma Scantlebury-White, the first Black female transplant surgeon in the United States, joined social worker Hannah Graves and kidney transplant recipient Mary Baliker to empower patients to take an active role in working with their healthcare team.

Each speaker had key takeaways for the audience: Mary recommended joining the transplant waitlist as soon as possible and staying in touch with your evaluation team because they are available to help. Hannah noted the waitlist can be a challenging process, comparing waiting for your matching kidney to waiting for your "true love." That is, the process cannot be rushed and it is worth waiting for a kidney that is the best match. Dr. Scantlebury offered encouragement and recommended starting the conversation about the need for a living donor with family members early in the process.

# COVID-19: Returning to Normal for the Immunocompromised

While many people may experience mild to moderate COVID-19 symptoms, people living with kidney disease or a transplant are at a higher risk of becoming severely ill with COVID-19. In this new session topic, Dr. Robert Montgomery and Dr. Sapna Mehta discussed how immunocompromised individuals can stay protected against COVID-19.

Dr. Mehta provided an engaging overview of monoclonal antibodies (antibodies made by cloning a specific white blood cell) and Evusheld. Dr. Montgomery shared his interesting perspective as a transplant surgeon and a heart transplant recipient. They also left the audience with a few recommendations: Dr. Montgomery advised people living with kidney disease or a transplant to remain careful when attending events while finding ways to re-engage in activities that are meaningful. Dr. Mehta recommended having conversations with your family, as well as your healthcare provider, about concerns regarding returning to normal.

These are just three of the 30 sessions from an inspiring Kidney Action Week!

Be sure to save March 20-24 for Kidney Action Week 2023!

Kidney Action Week was made possible by the generosity of Presenting sponsors Boehringer Ingelheim/Lilly and U.S. Renal Care, as well as Calliditas Therapeutics, Otsuka America Pharmaceutical, Inc. and Vertex Pharmaceuticals Inc.

AKF is also grateful for session sponsors Alnylam Pharmaceuticals, AstraZeneca and Satellite Healthcare.



## The four phases of clinical trials

Clinical trials are research studies that test new treatments before they are approved for people to use. The Food and Drug Administration (FDA) is the U.S. government agency that decides if new treatments or medical devices are safe and work well for people to use. Before the FDA can approve a new treatment for use in people, clinical trial results must show the treatment works and does not cause harm to people.

Most new treatments move through four phases of clinical trials. Each phase has different goals to make sure the treatment is safe and works well to treat a disease:

→ Phase	Length of time	Number of participants	Goals of the phase
Phase 1	Less than one year	20 to 100 participants who may be healthy or have the disease	<ul> <li>Learn how the treatment works in the human body</li> <li>Understand the best dose (amount) of the treatment</li> </ul>
Phase 2	A few months to 2 years	About 300 participants who have the disease	Learn more about how safe the treatment is for people to use
Phase 3	1-3 years	300 to 3,000 participants	Learn if the treatment works to
i naso o		who have the disease	<ul> <li>prevent, diagnose or treat the disease</li> <li>Learn more about safety and possible side effects</li> </ul>

Learn more at KidneyFund.org/clinical-trials

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Above: Agustin De La O Martinez (left) and Kat Velkoff (right)

### 'Better than meeting red pandas, says living kidney donor about donating her kidney to a stranger

at Velkoff has had some incredible experiences in her 31 years of life. She has traveled to 40 states (including Alaska), hiked part of the Appalachian Trail, performed Shakespeare and marched in color guard world championships every year since she was 16, winning four medals. She has even fed a banana to a rhinoceros and grapes to a red panda. But what tops the list of her experiences?

"The day I donated my kidney was by far the best day of my life," said Kat. "It's the best thing I ever did. Better than meeting red pandas."

Kat did a nondirected donation, choosing to donate her kidney to a stranger. She did not meet her recipient, Agustin De La O Martinez, until two days after their surgeries, which took place on Nov. 11, 2020. "I don't know what

I was expecting, but the second we met, we were both inconsolable," recalled Kat. "He's so sweet. He was only 24 at the time and had been on dialysis for four years and on the transplant waiting list for two years."

Agustin was born in Mexico, and as it turns out, he was born just one hour from where Kat's grandmother was born. "We were meant to be kidney buddies," she said.

While deciding to donate a kidney is a big decision for some, Kat has known she would become a kidney donor since college. After attending a bone marrow drive, she registered to be a potential bone marrow donor — and convinced her mom to register, too. In researching what becoming a bone marrow donor entailed, she discovered that she could also donate a kidney.

Kat remembered thinking, "I'm young, I'm in college and am dancing competitively, so I can't take time off to have a major abdominal surgery, but one day, I'll definitely donate a kidney. That's in my future, for sure. Why not?"

When the COVID-19 pandemic shut down everything, Kat decided it was the perfect opportunity to fulfill that plan. After discussing the decision with her family, Kat called her local hospital in August 2020 to begin the process of donating her kidney and was "immediately hit with this very long checklist of things you have to do before you can even be approved to donate a kidney."

Kat was surprised when her social worker added "buy life insurance" to that checklist. Her social worker explained that having only one kidney would be considered a pre-existing condition by life insurance companies that could then refuse to cover her or increase her premium payments.

When her social worker asked Kat if she planned to buy life insurance at their next meeting, Kat responded, "No. I'm going to change the law."

And that is just what she did.

About six months after her surgery, Kat took the next step in her kidney journey: becoming an advocate for other living organ donors. She wrote a letter to her local representative, sharing her story and living donor statistics for the state, and she soon began working with her on what would become House Bill 421, which would protect living donors from insurance discrimination.

Kat, who became an AKF Ambassador, eventually worked on a Virginia Senate version of the bill and testified in front of the Virginia General Assembly on behalf of the legislation multiple times. "This is an important issue. If

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#### Kidney donor, cont.



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they need someone to talk about it, I'll be that person. I'll keep talking."

One point that Kat reiterated was that living organ donation is not about the donor, it is about the recipient. She explained: "I wish lawmakers could understand that while this seems like a bill about saving living donors money, it's actually not about the donors. It's about our recipients and

making sure that they can get the organs they need to change their lives."

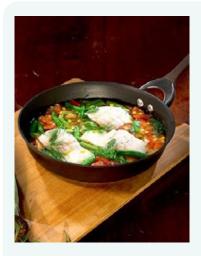
On April 11, 2022, Kat's hard work paid off when Gov. Youngkin signed this bill into law. With this new law, Virginia's grade on AKF's State of the States: Living Donor Protection Report Card improves from a C to a B. The Living Donor Protection Report Card measures seven types of legislation states should enact to provide protections for living organ donors and encourage living

donations. The average grade for the U.S. is a C.

"I'm hoping that this new law will reduce barriers for people who want to be living donors but are unsure about making that final commitment because of financial reasons, like they're afraid of losing their job or those higher life insurance premiums," said Kat, "Of course, the end result will be that somebody gets a kidney. So, the impact there is completely worth it – for the donors and the recipients."

### **Kidney Kitchen**

his delicate, yet flavorful one-dish meal combines summer's beautiful colors and tastes. Check out many more kidney-friendly recipes at 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.



#### **Poached Flounder with Summer Vegetables**



Makes: 4 low-sodium, medium-potassium, medium-phosphorus, medium-protein servings

Prep time: 10 min Cook time: 8 min

Recipe contributed by FamilyCook Productions

#### **Ingredients:**

½ cup sugar snap or snow peas, raw

2 ears sweet corn

1 small fennel bulb, sliced thinly

5 sprigs dill or chervil

1 cup water

1 large (12 ounces) flounder fillet

2 medium tomatoes

1 tablespoon olive oil

Pinch of pepper

Pinch of salt (optional)

#### **Directions:**

- 1. Cut the sugar snap peas in half on a diagonal.
- Slice the bottom of the corn off the cob and stand on the flat bottom. Slice the kernels off the ear
- 3. Remove the fennel fronds, dill and or other herb leaves from their stems. Chop coarsely.
- Heat the water in a small skillet. When the water begins to simmer (gentle rather than vigorous boil), add the fillets, corn and vegetables in the pan.
- Poach for about 6 minutes, or until fish is opaque and flaky. Adjust heat as necessary to ensure 5. the water is not boiling vigorously (or the fish may break apart).
- 6. Add the olive oil and season the broth with pepper and salt, if desired.
- Serve in shallow bowls. Ladle broth with vegetables on top of the fillets and enjoy!



Cooking Tip: When slicing kernels of ears of corn, stand the corn in the middle of a wide mixing bowls so the kernels gather into the bowl and don't fly off the cutting board.

In this recipe, you can use other types of fish as well. Great choices are trout, cod, and even tilapia. Frozen fish fillets can be used as substitutes too but remember to thaw them first.

#### **Nutrition facts**

(1 serving = 3 ounce fillet)

Calories = 173 Carbohydrates = 15 g Sugar = 6 g

Fiber = 3 g Calcium = 56 mg Fat = 6 q

Saturated Fat = 1 g Protein = 16 q Phosphorus = 217 mg Cholesterol = 48 mg Sodium = 138 ma Potassium = 597 mg



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

