



Jen Benson, New Canaan, CT  
AKF Ambassador



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# AKF in ACTION

Fighting kidney disease and helping people live healthier lives.

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## New educational resources on dialyzing at home

**A**KF recently launched three new resources on home dialysis to help people learn more about whether it is the best treatment option for them. These resources include materials on comparing home dialysis options, information on home dialysis myths and a home dialysis decision aid.

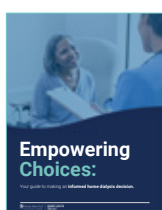


A comparison fact sheet highlights the different aspects of dialysis options, from home to in-center modalities, and how they fit into a person's life.



"Fact or Fiction: Home Dialysis Myths Debunked" lays out the facts about common misconceptions surrounding home dialysis, including safety, the impact it has on a person's ability to travel, family planning considerations, the need for a care partner and more. This section also

debunks several myths surrounding peritoneal dialysis, another home treatment for kidney failure.



The Home Dialysis Decision Aid tool provides important information about the various dialysis options so that people with kidney failure, their loved ones and their doctors can make health care decisions together. Dialysis is not a one-size-fits-all treatment, and this tool



explains the different factors to consider when choosing an option that will best suit a person's lifestyle.

To explore AKF's new home dialysis resources, which were developed as part of AKF's Kidney Health for All™ initiative, visit [bit.ly/HomeDialysisResources](https://bit.ly/HomeDialysisResources) or scan the QR code below.

To explore AKF's  
new home dialysis  
resources, scan this  
QR code.



# All about cardiovascular-kidney-metabolic (CKM) syndrome

**O**n Oct. 9, the American Heart Association (AHA) published a new advisory redefining cardiovascular disease (CVD) risk, prevention and management. The advisory found that there is an overlap between CVD, kidney disease, type 2 diabetes and obesity, and it defined and officially declared CKM syndrome as a specific health condition.

CKM syndrome is a condition in which a person has several health problems that overlap. These health problems may cause an individual to have a higher chance of developing a heart-related disease, such as a stroke, heart attack or heart failure. Kidney disease can cause heart disease, and heart disease can cause kidney disease.

CKM syndrome is divided into five stages of risk, from stage 0 (no risk) to stage 4 (highest risk). There is screening and treatment that is recommended for each stage of CKM, including stage 4, which involves people with kidney failure. People in this stage usually feel and show signs of heart problems, and they may have already experienced a heart attack, stroke or heart failure. People in stage 4 of CKM syndrome should see their doctors to receive personalized treatment for heart disease and other CKM syndrome conditions.

Even though there is more to learn about CKM, the AHA's advisory raises awareness about the disease and can help people make educated health care decisions. If you are concerned or have questions about CKM, talk to your health care provider. You can also view AKF's webpage on CKM by visiting [bit.ly/CKMInfo](https://bit.ly/CKMInfo) or scanning the QR code at right.

To learn more about CKM scan this QR code:



# Thriving on your terms: "Dialysis at Home" summit recap

**M**ore than 1,600 people registered for the "Dialysis at Home: Kidney Community Event," a free and virtual event that connected people across the kidney community to learn about the latest updates, tools and resources to help individuals advocate for their best care while managing kidney disease on home dialysis.

Here are highlights from select sessions of the summit:

## Patient Advocate Panel: To Each Their Own—Four Different Dialysis Paths

Four dynamic panelists shared their unique journeys with kidney disease and emphasized that it is important for people with kidney failure to listen to their bodies and do research to ensure they are comfortable with the dialysis modality they choose.

## It Takes a Village: Being Successful at Home

Participants heard from some of the common players on a dialysis care team, such as a home dialysis nurse, renal dietitian, social worker, nephrologist and care partner.



## Navigating Challenges: Q&A With Patient Advocate

Home dialysis advocate Erich Ditschman and summit emcee David Rush answered questions from participants and shared their personal journeys on what it takes to be successful at home.

Watch all the summit sessions on replay on AKF's YouTube channel ([bit.ly/YouTubeHDUSummit](https://bit.ly/YouTubeHDUSummit)).

*"Dialysis at Home: Kidney Community Event" was made possible by the generosity of Leading Sponsor Outset Medical (sponsoring the panel "It Takes a Village: Being Successful at Home") and Exhibit sponsors Ardelyx, Inc., AstraZeneca, Baxter International Inc., NxStage Medical Inc., TNT Moborg International Ltd and U.S. Renal Care.*

# Financial assistance programs of the American Kidney Fund



## **Health Insurance Premium Program:**

Provides access to lifesaving medical care for low-income dialysis and transplant patients by ensuring these individuals can maintain their health insurance coverage.



## **Safety Net Program:**

Provides grants to help people with health care expenses that are not covered by insurance, including transportation to dialysis, over-the-counter medicines, copays and other needs.



## **Disaster Relief Program:**

The nation's only rapid-response program that provides emergency financial assistance to dialysis and recent transplant patients in the wake of natural disasters. Grants are used for transportation, temporary housing, kidney-friendly foods, medicines and replacing personal essentials.

# Our virtual assistant can help!

**T**o provide more options for patients, caregivers and renal professionals, AKF has a virtual assistant in the Grants Management System (GMS) to better respond to user questions. The virtual assistant is available for solving issues with:

- Login/registration page of GMS
- Navigating GMS and locating instructions
- Grant request payments and statuses

## What can the virtual assistant do?

### **GMS registration walkthrough**

Our virtual assistant can assist you through every step in the registration process.

### **Grant requests, payments and statuses**

Our virtual assistant can now help guide you and answer questions related to grant request payments and statuses.

### **Eligibility FAQs**

Within our Frequently Asked Questions section of the virtual assistant, you'll be provided an eligibility criteria walkthrough.

### **Application process FAQs**

Use our virtual assistant to understand the basics of the application process. This will help get you started once you've logged into GMS.

## Ways to contact AKF



**GMS Assist:** Visit [GMSassist.com](https://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](https://gms.KidneyFund.org).



**Phone:** Call us at **(800) 795-3226** Monday through Thursday 11 a.m. to 2:30 p.m. ET to speak with a live representative.



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# Home (dialysis) for the holidays

**F**or many of us, the holidays involve traveling to visit family, friends and loved ones, or just taking a vacation. While holiday travel can bring us joy and great memories, it can also involve stress and anxiety. For people with kidney failure who use home hemodialysis, this stress and anxiety is only magnified. However, with preparation, people on home hemodialysis can travel safely and enjoy the holidays while getting the lifesaving treatment they need.

“Travel is definitely doable, but it requires an incredible amount of advanced planning,” said Nieltje Gedney, former executive director of Home Dialyzors United. While traveling, home hemodialysis users have two options for receiving their treatment: take their dialysis machine with them or arrange to go to a clinic at their destination. For those who choose to bring their machine with them, flying is the best option if driving is not feasible.

“The Federal Aviation Administration covers the airports, while the airlines are covered by the Department of Transportation (DOT),” Nieltje said. “Unfortunately, with buses and trains, there is no requirement for these modes of transportation to accept dialysis devices from passengers.”

When flying with dialysis equipment, people should call the disabilities desk at their respective airline. “Get in your record that you are traveling with a life-assisting medical device,” Nieltje said. People should then figure out how to get themselves, their equipment and their luggage from their car to the airport. “I recommend using ‘Pay to Park,’ ‘Park and Ride’ or ‘Park and Fly’ services, where you keep your car at a hotel and the hotel shuttle brings you

to the airport,” Nieltje said. “They will help you with your luggage and bring you right to your airline gate.” Nieltje also stressed that travelers should visit the websites for the airports they will be using and familiarize themselves with their layouts and ADA features.

Although it is federal policy under the Air Carrier Access Act of 1990 (see [bit.ly/AirCarrierAccess](https://bit.ly/AirCarrierAccess)) for airlines to allow people to bring life-assisting medical devices onboard for free, not all airline staff are aware of this. “I usually encourage people to make a copy of the regulation and hand it to airline staff when they’re checking in,” said Nieltje. Even if the airline has specific policies, the federal policy will always trump those. If an airline continues to hassle people, those passengers have a right to file a complaint with the DOT.

People who choose to receive dialysis at a clinic while they are away also need to plan in advance. Nieltje recommends that people arrange their treatment at least six weeks before their trip and said it’s critical to confirm an appointment several times. This is especially important during the holiday season, as clinics are typically not open on major holidays and can be in high demand this time of year.

For more detailed information about traveling with home dialysis equipment, including getting through airport security, boarding your mode of transportation and bringing your equipment and luggage to hotels and lodging, visit [homedialyzorsunited.org](https://homedialyzorsunited.org) or AKF’s webpage on traveling with kidney disease: [bit.ly/AKFTravelDialysis](https://bit.ly/AKFTravelDialysis).

Visit [bit.ly/HomeDialysisResources](https://bit.ly/HomeDialysisResources) for more information on home dialysis.

*We are extremely saddened to report that Nieltje passed away in September 2023. She was a tireless advocate for helping more people dialyze at home, and her work was invaluable in improving patient quality of life.*

## AKF staff spotlight



**Name:** Eric Vicks

**Hometown:** Cincinnati, Ohio

**What do you do at AKF?** I am the Director of Patient Advocacy. I help AKF patient Ambassadors find their voice and share their experiences in order to improve policies, rules and legislation impacting people with kidney disease.

**What is your personal connection to kidney disease?** I have several members of my extended family who are currently fighting kidney disease.

**Why are you passionate about fighting kidney disease?**

I am driven by the belief that everyone deserves access to quality health care and the opportunity to live a healthy life. By advocating for support of kidney disease, I hope to contribute to the development of better treatments, improved patient care and ultimately, a world where kidney disease is no longer a debilitating condition.

**What is the best part of your job?** I get to speak to and hear from the people I advocate for and get to share milestones in their lives.

**What are your favorite hobbies outside of work?** My hobbies are reading books, creative writing and cooking.

# Talk with your doctor about treating pruritus (itchy skin)

**Pruritus is distressing, itchy skin, which is common in people on dialysis.** The itchy feeling can be so constant and uncomfortable that it may disrupt your sleep and affect your quality of life. The good news is there are treatments to help.

**Talk with your doctor or dialysis care team about your itchy skin, even if you have asked them in the past.** This guide will help you make a plan with your doctor to treat or prevent pruritus.

## Get ready for your next doctor visit

- **Be prepared to talk about the pruritus symptoms you have been feeling.**
- **Write down a list of questions to ask your doctor.** Consider the questions on the next page.
- **Bring a pen and paper to write down what your doctor says.** You can also ask a friend or family member to go with you and take notes or ask your doctor to print out the important information for you.

## Describe your symptoms in detail



Be open about your symptoms, even if you feel embarrassed—it helps your doctor give you the right care.

### Your pruritus symptoms

- How long have you had itchy skin?  
\_\_\_\_\_
- On what parts of your body have you had itchy skin?  
\_\_\_\_\_  
\_\_\_\_\_
- What home remedies or treatments have you used for itchy skin?  
\_\_\_\_\_  
\_\_\_\_\_
- The treatments I have used:  
☐ Do not help   ☐ Help some   ☐ Help a lot
- Think about the last month. How would you rate your symptoms? Circle one.  

0

1

2

3

4

5

6

7

8

9

10

No itch

Worst imaginable itch



Learn more about pruritus and kidney disease at [KidneyFund.org/Pruritus](https://www.kidneyfund.org/Pruritus)

## Ask your questions



During your visit, you may have limited time to ask all of your questions.

**Write a number next to each question** to rank them from most to least important. Start with 1 for the most important question that you want to ask first, in case you run out of time.

If you cannot print this guide, use a notebook or your phone to track your symptoms, write your questions, and take notes.

### Questions to ask your doctor

☐ What can I do at home to help prevent pruritus? Are there any products I should use or avoid? Lotions? Soaps? Laundry products?

\_\_\_\_\_

☐ What foods should I limit or avoid?

\_\_\_\_\_

☐ What are my blood levels of calcium, magnesium, phosphorus and parathyroid hormone? (High levels of these natural body chemicals may help cause pruritus). If they are not in a normal range, what should I do?

\_\_\_\_\_

☐ What pruritus treatments can help me?

\_\_\_\_\_

☐ My other questions:

## Check that you understand what your doctor said

Repeat what your doctor said back to them **in your own words**. You can say:

**"I want to make sure I understand..."** (repeat the information). **Did I get that right?"**



# AKF brings Rare Kidney Disease Advocacy Day to Capitol Hill

**O**n Sept. 21, AKF hosted its first Rare Kidney Disease Advocacy Day on Capitol Hill, connecting patient advocates from the IgA Nephropathy (IgAN) Foundation, health care professionals and members of AKF's Unknown Causes of Kidney Disease (UCKD) Coalition with lawmakers on Capitol Hill. Representing seven states, nine advocates, all of whom have a rare kidney disease, had 23 meetings with their senators' and representatives' offices.

Participants urged Congressional offices to co-sponsor the Living Donor Protection Act of 2023 (H.R. 2923/S. 1384)

and asked representatives to support the New Era for Preventing End-Stage Kidney Disease Act, which is expected to be introduced in the current Congress.

AKF is grateful to its corporate sponsors whose support made this event and the UCKD Project possible: Title Sponsors Novartis and Traveo Therapeutics, Leadership Sponsors Otsuka America Pharmaceutical, Inc. and Vertex Pharmaceuticals Inc., and Champion Sponsors Alexion, AstraZeneca Rare Disease, Amgen, Natera and Sanofi.



*Eric Vicks, Senator Cindy Hyde-Smith and Cindy Ross*



*Britta Dornan of NephCure, Congressman Gus Bilirakis, Dr. Julie Wright Nunes and Carlos Cristi*



*Malkia White*

# Thank you to our corporate members for their support in 2023

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# Giving patients on Velphoro a *Voice*

Real patients share their experiences with Velphoro



"Ever since we switched my phosphate binder, my phosphorus has been spot on."

—Robert



"The flexibility was great for me. I could chew it, I could crush it, or I could break it."

—Antonio

Watch patient videos at **VelphoroVoices.com**.

Scan code with your smartphone camera.

The paid testimonial provided is representative of that individual's experience, and not all patients may experience these benefits.

## Interested in being a part of Velphoro Voices?

If you have experience with Velphoro, your story could help motivate other patients on dialysis. Fill out this form to be considered as the next voice of Velphoro!



Tell us your story at

**BeTheNextVelphoroVoice.com**

### 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](http://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](http://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/](http://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](http://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](http://www.fmcna.com/patents)

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# A can't-miss dessert recipe from AKF's Kidney Kitchen®

**A** must-try dessert recipe at your next holiday gathering. It will delight you for an entire week if stored in tin foil at room temperature. It is especially good toasted or with a dab of butter. Be sure to check out [KidneyKitchen.org](http://KidneyKitchen.org) for more than 700 kidney-friendly recipes!



## Holiday Panettone

**Makes:** 10 Servings  
**Serving size:** 1 slice



**Prep time:**  
1 hour 15 min

**Cook time:** 50 min

Recipe contributed by  
FamilyCook Productions



### Cooking Tip:

Activating yeast can be tricky. Adding a teaspoon of sugar and keeping the yeast/milk mixture in a warm area can help with activation and mixture foaming.

### Ingredients:

1 teaspoon saffron  
2 tablespoons water  
½ tablespoon vodka or rum  
4 cups unbleached flour  
⅔ cup sugar  
¼ teaspoon nutmeg, ground  
¼ teaspoon cinnamon, ground  
¼ teaspoon cardamom, ground  
Pinch of sea salt

6 ounces (175 grams) cold unsalted butter, cut into cubes, plus extra for greasing  
1 packet (7 grams) dried yeast  
⅔ cup warm milk (lukewarm, 110°F)  
3 tablespoons golden raisins  
3 tablespoons brown raisins  
3 tablespoons candied ginger, diced  
1 egg, beaten  
1 tablespoon milk

### Special Equipment:

Loaf Baking Dish

### Advance Prep:

Bring a small pan of water to boil. Combine saffron with 2 tablespoons of boiling water in a small bowl. Add alcohol and reserve overnight to infuse at room temperature.

### Directions:

1. Butter a loaf baking dish.
2. Combine flour, sugar, cinnamon, cardamom and salt in a large mixing bowl.
3. Work the butter into the flour, using a pastry cutter or your very clean fingertips, until the mixture resembles coarse breadcrumbs.
4. Combine the yeast and warm milk in a small bowl. Place bowl in a warm spot and wait for a few minutes for the yeast to activate and form a light froth.
5. Create a well in the center of the flour mixture. Pour activated yeast into the well.
6. Add the infused saffron water. Stir until combined.
7. Knead the mixture for about 10 minutes to form a soft cohesive dough.
8. Add the golden raisins, brown raisins and candied ginger, and continue to knead for a few minutes until the dough is smooth.
9. Place the dough into the prepared loaf dish.
10. Smooth the top with the back of a spoon. Cover with a dish towel and leave in a warm place until the dough has doubled in size (this can take up to 3 hours, depending on the temperature of the room).
11. Preheat oven to 400 degrees Fahrenheit.
12. Mix the beaten egg with the 1 tablespoon of milk in a small bowl. Brush the surface of the loaf with the egg mixture.
13. Bake for 40 to 50 minutes, until the top is golden brown.
14. Allow the loaf to cool on a wire rack.
15. Slice into 10 pieces before serving.

### Nutrition facts

(1 serving = 1 slice)

Calories = 414  
Carbohydrates = 62 g  
Sugar = 22 g

Fiber = 2 g  
Calcium = 40 mg  
Fat = 16 g  
Saturated Fat = 9 g

Trans Fat = <1 g  
Protein = 7 g  
Phosphorus = 94 mg  
Cholesterol = 58 mg

Sodium = 36 mg  
Potassium = 162 mg



*wishing you a*  
**BRIGHT SEASON OF JOY!**

