



WINTER 2020 | VOL. 5.5

AKF in Action


Fighting kidney disease and helping people live healthier lives.

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Introducing AKF's new partnership with Backpack Health

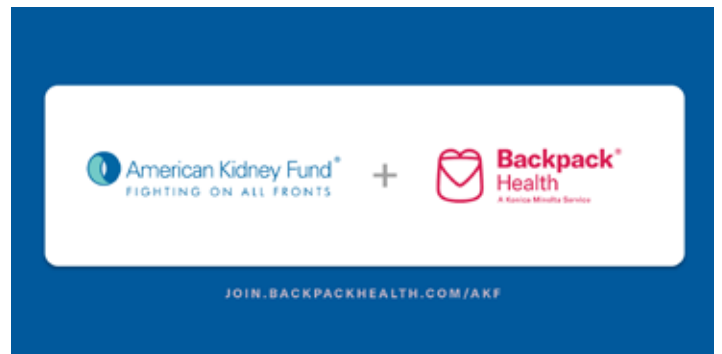
As a kidney patient, you know how challenging it can be to keep track of medical records from multiple specialists and medical facilities. The American Kidney Fund (AKF) recently announced a new partnership with Backpack Health, a service of Konica Minolta, a digital health records management tool. If you need a better way to manage your health records, this free tool could be the solution.

Through AKF's group on Backpack Health, you can consolidate all your health information, including lab results and medicines, into one convenient, private and secure cloud-based location. The name Backpack refers to how you can keep all your records together in one place and take it with you, just like a real backpack, to all your doctors' appointments.

What is Backpack Health and how do I use the group?

Backpack Health is a place where you can store your medical records. People with kidney disease usually have multiple other conditions, such as diabetes and high blood pressure, and are typically under the care of many doctors and specialists. We know that keeping track of everything can feel like a full-time job. That is where the AKF Backpack Health group comes in.

You can upload your health information to the platform, so you can have easy access to it whenever



and wherever you need it. Things you can add to your Backpack Health profile include lab results, kidney-friendly meal plans, doctors' notes, prescriptions and more. Your Backpack Health profile can be accessed via their website or mobile app, meaning you can get rid of those bulky binders and file folders you lug with you between doctors' appointments.

Your health information can be easily shared with your caregiver(s), other family members, a travel partner and others. You can share information with all your doctors, so you do not have to make or pay for copies of medical your records. Your doctors can also update your records right in the platform, and they will be able to see the notes from your appointments or lab work with another doctor, which can help all the members of your care team better treat you.

If you want to discuss your labs more thoroughly with your nephrologist at your next appointment, you can make a reminder note for yourself in your Backpack Health profile. If you have a question about whether you can eat a certain food, you can add it to your profile

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AKF's new partnership, cont.

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so you do not forget to ask your dietitian next time you see them. The Backpack Health technology exists to help make your life easier.

How do I join AKF's group?

You can join the AKF kidney disease group on Backpack Health at join.backpackhealth.com/akf.

Is my information secure?

As Backpack explains on their website: "All of the information you store on Backpack Health is encrypted. Information stored in the cloud is encrypted in our database, and 256-bit encryption protects data sent over the network and secure HTTP (HTTPS) sessions. Threat-detection services monitor Backpack Health's systems continuously for unauthorized or malicious activity. And you can also keep your data extra safe on all of your devices by enabling two-factor authentication."

You can learn more about Backpack Health's account security and privacy policy at backpackhealth.com.

What if I don't want to upload all my health information?

You are in control. You decide what information you want stored in your Backpack Health profile, and when you share it with others, you decide which records to share. No one has to see your full medical history if you do not want them to.

What if English is not my first language?

Backpack Health can easily translate your information into multiple languages, which can remove potential language barriers between you and your care team.

What else can I do in the AKF group besides manage my medical records?

Members of the AKF Backpack Health group will be able to access AKF's award-winning educational content about kidney disease, participate in surveys to help us identify unmet needs of kidney patients, and learn about opportunities to participate in clinical trials.

What if I need help?

You can contact Backpack Health through the "Contact Us" option in the mobile app or on their website—backpackhealth.com/contact—or simply email help@backpackhealth.com.

AKF staff spotlight



Name: Kristina

Hometown: Hudson Valley, New York

What do you do at AKF?

I am the social media manager at AKF, which means I write and post most of what you see if you follow us on Facebook, Twitter, Instagram and LinkedIn. Though I am a member of our communications and marketing team, I work across all of AKF's departments to support our digital campaigns. I am always looking for new and exciting ways to share kidney stories from our community.

Why are you passionate about fighting kidney disease?

When I got started in my career, there weren't a lot of easy-to-follow resources for patients who are living with a chronic disease, and I wanted to help change that. Working at AKF, I have learned just how important and powerful our kidneys are in our bodies—they help our bones, blood, heart and more. I'm so glad I learned what powerhouses these small organs are, and that caring for them means taking better care of myself. My AKF colleagues and I have the chance to share that knowledge with millions of people—and save a lot of lives in the process.

What is the best part of your job?

The kidney community! I am amazed at how kind, resilient and strong kidney patients are. Kidney patients and living donors are like superheroes to me. It's very rewarding to be able to learn more about their stories and triumphs each day, as well as join them along their kidney journeys at every stage.

What are your hobbies outside of work?

I love to dance. A number of my friends are DJs, so I'm often on the move to see their shows. I also have experience in the fine-dining industry, which has helped me discover a love for food and service. I'm always trying a new restaurant or dish and offering *unsolicited* reviews to my friends. Sometimes I post reviews on social media as if I were a real food critic (hah!). Growing up in a small town, the mountains are my happy place, so I also really enjoy hiking, camping or stargazing when the weather is nice.



Meet your treatment team: Nephrologist

A nephrologist is a doctor who specializes in caring for the kidneys. Your nephrologist is a very important member of your health care team. Your nephrologist cares for you by helping you understand your kidney condition, putting together a treatment plan and connecting you to other resources that can help.

Understanding your condition

During your first visit with your nephrologist, they will ask questions about your medical history and lifestyle and do a routine physical to get to know you and the reason for your visit.

If you do not know the cause of your kidney disease, your nephrologist will work to figure out what is damaging your kidneys.* In addition to common kidney function tests, like blood and urine tests, a nephrologist might also suggest a kidney biopsy to help determine what is causing your kidney problem. They may also look at your family history to see if there is a genetic cause to your kidney disease or if you may have a rare disease that is causing damage to your kidneys.

At future appointments, your nephrologist will explain your test results, go over next steps and answer any questions you may have. It may be helpful to bring a notebook with questions you have thought of ahead of time to ask your nephrologist and also to write down important information they tell you during your appointment. There is no need to feel embarrassed if you do not understand something. Ask as many questions as you can!

Putting together a treatment plan

Using the test and diagnosis results from your first appointment, your nephrologist will prescribe a treatment plan for you. Your treatment plan will depend on your stage of kidney disease, but it can include:

- Medicines to treat the cause of your kidney disease or complications you may have from your kidney disease. These medicines can help control diabetes and high blood pressure—the two leading causes of kidney disease—or complications like anemia, gout, high phosphorus or high potassium.
- Dialysis. There are two types of dialysis—hemodialysis and peritoneal dialysis. Hemodialysis can be done either in a dialysis center or at home after you and a caregiver have been trained to do your treatments. Peritoneal dialysis is done at home.
- Kidney transplant. A kidney transplant is considered the best treatment option for most people with kidney failure because it can increase your chances of living a longer, healthier life.

Your nephrologist may also recommend taking other steps to protect your kidneys. These could include changing the way you eat, exercising more often, and limiting tobacco and alcohol.

Remember—there is no cure for kidney disease or kidney failure. Once in kidney failure, you need dialysis or a kidney transplant to live. It is important to stick to your nephrologist's treatment plan to help protect your kidneys as much as possible.

Connecting you to other resources

Your nephrologist will work with other health care professionals to make sure you receive the treatments they prescribed. This may include:

- Referring you to a renal dietitian who can help you find healthy, kidney-friendly foods
- Helping you find a dialysis center that is close to your home
- Referring you to a transplant surgeon

Your nephrologist is more than just your doctor—they are a core member of your health care team and a long-term partner in your fight against kidney disease.

**If the cause of your kidney disease is still undiagnosed, you may want to visit another nephrologist for a second opinion. Knowing the cause of your kidney disease will help you get the best treatment and outcomes.*

Kidney Kitchen

Chestnuts make this a richly flavored soup that is ideal as an appetizer for a holiday meal. 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.



Chestnut Celery Root Soup

Makes: 12 low-phosphorus, low-potassium, low-protein, low-sodium servings



Prep time: 30 min

Cook time: 45 min

Total: 1 hr 15 min

Recipe contributed by
FamilyCook Productions

Nutrition facts (1 serving = ½ cup)

Calories = 119

Carbohydrates = 19 g

Sugar = 5 g

Fiber = 2 g

Calcium = 52 mg

Fat = 4 g

Saturated Fat = <1 g

Protein = 2 g

Phosphorus = 92 mg

Cholesterol = 0 mg

Sodium = 105 mg

Potassium = 297 mg

Ingredients

3 tablespoons olive oil

2 cups fresh chestnuts, precooked
and peeled

3 $\frac{2}{3}$ cups celery root, diced

$\frac{1}{4}$ cup celery, chopped

$\frac{1}{4}$ cup onion, chopped

$\frac{1}{4}$ teaspoon sea salt

Black pepper, to taste

3 $\frac{1}{2}$ cups water

1 cup unsweetened rice milk or
whole milk

Chives, chopped, for garnish

Instructions

1. Heat oil in a large stockpot over medium heat.
2. Add the cooked chestnuts, celery root, celery and onion. Season with salt and pepper.
3. Cook for 10 minutes on medium heat until vegetables start to soften.
4. Add water to the pot. Simmer for approximately 20-30 minutes, until vegetables are completely cooked through and soft enough to puree.
5. Add milk and return to a boil.
6. Remove from heat. Blend into a puree using an immersion blender, or in batches using a large high-speed blender.
7. If the texture is not smooth enough using your blender, strain through a fine mesh strainer before serving. Garnish with chopped chives and serve.

Tip: To make a more flavorful soup, use 2 cups of stock + 1 $\frac{1}{2}$ cups of water instead.

wishing you a **HEALTHY
THANKFUL
& JOYFUL**
holiday season

Brothers, best friends and the perfect match

Jeremy Smith and his brother, Drew, have been best friends since they were kids. Now both in their 30s, they have spent decades doing everything together—playing on the same sports teams, taking an annual snowboarding trip to Lake Tahoe, hanging out in the same group of friends, attending the same college and even once following each other in a move across the country.

But in 2020, they also went into surgery together when Jeremy donated his kidney to Drew.

Drew found out that he had kidney disease by chance. During his sophomore year of college, he came down with bronchitis and went to his doctor, who ordered routine blood work. After reviewing the results, the doctor found an elevated creatinine level, which indicated that his kidneys were not functioning as well as they should be. Drew went through several additional tests and eventually learned that renal reflux—a backflow of urine into the kidneys—was the cause of his kidney disease.

In 2019, Drew’s kidney disease progressed to kidney failure. He began peritoneal dialysis at home and a yearlong search for a living kidney donor. Their mom, dad and multiple close friends were all tested to see if they could donate a kidney to Drew, but it was Jeremy who was the perfect match.

Jeremy spent a year prepping for the transplant. He changed his entire lifestyle so he could be his healthiest for the surgery. He got COVID-19 back in March, but fortunately recovered. Jeremy says that the pandemic lockdown was the “perfect storm” because it allowed him to do pretty much nothing else except focus on being ready to give Drew his kidney.

The transplant was supposed to take place early in the summer, but it was postponed to October due to COVID-19. Jeremy flew from New York City, where he lives, to San Francisco, where Drew lives, for the surgery. Jeremy successfully donated his kidney to Drew on October 8, 2020.

The hospital was very cautious during intake because of the pandemic. Everyone had to test negative for COVID-19 prior to arrival at the hospital, then go through multiple screening procedures before admittance to the preop room. After the surgery, Jeremy and Drew went straight to their recovery rooms, which



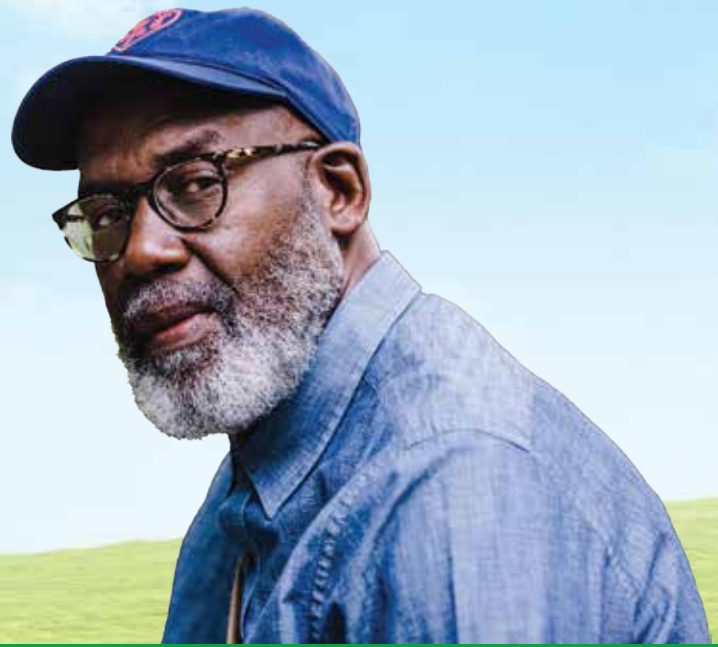
Above: Jeremy (left) and Drew (right) Smith

were sanitized multiple times a day. All hospital staff wore masks the entire time, and all patients were required to wear masks whenever outside of their rooms and when interacting with staff. Jeremy was able to get up and moving on day two after the surgery, so by day three the hospital felt that he was in stable enough condition to be released. Drew stayed in the hospital for five nights prior to being released. For the next two weeks, they both recovered in a house located in the Sunset district in San Francisco, relaxing and enjoying the beautiful weather and sights of the Golden Gate City.

The perfect storm created by the coronavirus pandemic also gave Jeremy the time to give back to the kidney disease community. Inspired by Drew and friends who lost parents to kidney disease, Jeremy signed up for AKF’s do-it-yourself fundraising platform, KidneyNation. Jeremy started a KidneyNation fundraising page and also hosted a backyard concert at their family farmhouse in Pennsylvania, featuring the Grammy-nominated band Yarn, to raise additional funds. Determined to raise money for AKF as a tribute to Drew before the transplant surgery, Jeremy reached out to his network of family, friends and coworkers to get as many donations and sell as many concert tickets as he could. His fundraising efforts were so successful, he exceeded by thousands of dollars his goal of raising \$8,500 for AKF’s programs and services, for a total of more than \$12,100.

Since the transplant surgery, Jeremy and Drew have continued recovering together by the beach in San Francisco. They plan on being in top shape to hit the Tahoe slopes again this winter.

Know someone diagnosed with ADPKD?



Autosomal Dominant Polycystic Kidney Disease (ADPKD) is a genetic condition, meaning it can be inherited from a parent or both parents.

If you have ADPKD, you may know a family member who also has ADPKD, and who would qualify for an ongoing clinical trial investigating the safety and effectiveness of an investigational drug. Researchers are studying how the drug might affect the progression of ADPKD, as well as the kidney function of participants in the study.

You may qualify for this clinical trial if:



You have been diagnosed with PKD by a physician



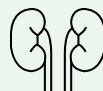
You are not on dialysis



You are man or woman between the ages of 18 and 50 years old



You have been successfully managing your blood pressure with anti-hypertension medication for at least 30 days



Your kidney disease is at risk for rapid progression

[Learn more at PKDClinicalTrial.org](https://www.pkdcclinicaltrial.org)

Real participant reviews of some of AKF's recent webinars:

"Brilliant presentation by an obviously knowledgeable practitioner. Facts were presented in a way to make you remember and the Q & A session was a learning avenue on its own."

"Great webinar with concrete information that can be immediately useful on a daily basis!"

"I enjoyed the webinar. I learned new information. The slides were helpful in understanding the topic."

"Although we scoured the internet for information, this session was eye-opening, easy to understand and more informative than doctors' advice and any information we have read online."



WATCH AND LEARN:

AKF webinars available on demand

AKF hosts free monthly webinars on many important topics relating to kidney disease. We record all of our webinars, so if you can't watch them live, you can always watch them later at your convenience at KidneyFund.org/webinars.

Kidney-friendly holidays

The holiday season is a time for family, friends and food. When you have kidney disease, it can be hard to know what holiday foods to choose to help you stay healthy. This webinar will help you learn more about enjoying the holidays with kidney-friendly foods. **What you'll learn:** healthy holiday foods for people with kidney disease, ways to modify holiday menus to make them kidney-friendly, how family and friends can help people with kidney disease eat well during the holidays.

Managing side effects of late stage kidney disease

Did you know that many of the side effects of late stage kidney disease and kidney failure can be managed? You do not need to suffer through these uncomfortable experiences without help! **What you'll learn:**

strategies to manage dry, itchy skin related to kidney disease, post-dialysis fatigue and recovery, sleep disorders in advanced kidney disease, resources for support.

Living kidney donation: Everything you need to know

A living kidney transplant is often a life-changing event for both the recipient and their donor. Anyone considering a kidney transplant or becoming a living donor should know all the facts about the process to make the most informed decisions about their health. **What you'll learn:** an overview of the living kidney donation process, common myths and concerns held by people who are considering donating a kidney, how kidney donation affects the health of the donor, financial considerations for living donors.



Questions about setting up a new Grants Management System (GMS) patient profile?

Need to reclaim your existing profile? See our step-by-step guide at KidneyFund.org/gms-registration.



American Kidney Fund®
FIGHTING ON ALL FRONTS

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Suite 300
Rockville, MD 20852
800.638.8299

KidneyFund.org

Find important COVID-19 information and resources at KidneyFund.org/coronavirus.

WHAT'S INSIDE:

- AKF's new partnership with Backpack Health
- Meet the treatment team: Nephrologist
- Transplant story
- Winter recipe





VELPHORO

On dialysis,
trying to manage phosphorus?

lighten your day

THE VELPHORO WAY

- Velphoro® (sucroferric oxyhydroxide) is a stronger phosphate binder. Because it's stronger, you can take fewer pills...and lighten up your whole day
- Velphoro is easy to take. Most people were able to maintain phosphorus control with only 3 or 4 tablets per day*—not 3 or 4 per meal as with some other binders

Find out more at www.velphoro.com, and ask your doctor if Velphoro is right for you

*The recommended starting dose of Velphoro is 3 tablets (1,500 mg) per day.

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.

For more information please see accompanying brief summary of full Prescribing Information, or visit www.velphoro.com.



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PN103781-02 Rev. A 09/2019

 **VELPHORO®**
(sucroferric oxyhydroxide)
chewable tablets

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 overdose 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:

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Waltham, MA 02451

Patents apply, visit www.fmcna.com/patents

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