issue number 20

The Citizen Kidney

A publication of Dialysis Patient Citizens (DPC) Education Center

DPC EDUCATION CENTER

President's Message

Greetings to all readers of The Kidney Citizen! We at Dialysis Patient Citizens (DPC) Education Center are committed to providing dialysis patients and caregivers with the information they need to live better, longer lives. In this issue, I'd like to highlight the importance of innovative treatments that can improve the health and well-being of you and your loved ones.

Thanks to ongoing innovation, new therapies are helping patients control phosphorus levels—an essential factor in preventing complications like clogged arteries and unhealthy veins, which often make patients ineligible for transplant. Too often, patients only learn about the importance of their phosphorus levels when they are laying in a hospital bed. But knowledge is power, and with the right education, patients can take proactive steps to protect their future. Previously, many patients relied solely on dietary restrictions and traditional phosphate binders that were difficult to tolerate. However, new therapies offer more effective ways to regulate phosphorus with fewer side effects, giving patients a better chance at maintaining their health and preserving their eligibility for transplant. Understanding these treatments and how to access them is essential for every dialysis patient.

Innovation in dialysis care goes beyond phosphorus management. Scientists have developed innovative treatments that help prevent infections, improve access site health, treat anemia, and even reduce the severe itching (pruritus) that many dialysis patients experience. These advancements can make life on dialysis more manageable and help patients not just manage their condition, but thrive in the process. However, in order to reach their health goals, dialysis patients need to know what is available to them. That's where DPC's Education Center plays a crucial role. DPC's Education Center provides the resources patients need to stay informed about the latest therapies. Through online courses, expert guidance, and dialysis patient community support, we ensure that dialysis patients have the tools to advocate for themselves and make educated decisions about their care. No patient should feel left in the dark about treatment options that could change their life.

Unfortunately, current Medicare payment policy is not favorable to new therapies, which has made providers reluctant to offer them. DPC has been focused on addressing this problem in Washington. As dialysis care continues to evolve, we are dedicated to keeping you informed. We encourage you to explore the DPC Education Center and continue reading The Kidney Citizen to stay up-to-date on the latest innovations in kidney care. If you have any questions, please don't hesitate to reach out. We are here to help.

Thank you for being a part of our community!

Sincerely,

Merida Bourjolly

Merida Bourjolly,
President of DPC Education Center Board of Directors

CEO's Message

As we celebrate the 20th anniversary of Dialysis Patient Citizens (DPC) and reflect on our progress, we are also looking ahead to the opportunities and challenges facing the dialysis community. One of the most pressing concerns for DPC and dialysis patients today is the growing gap between innovation and care. While exciting new therapies and treatments are emerging, too many patients are left behind due to outdated payment policies and the resulting underinvestment that makes innovative treatments inaccessible. We are committed to fixing that.

One of the causes of this challenge is that Medicare payments from the Centers for Medicare & Medicaid Services (CMS) are lagging increases in providers' costs, which restrict the system's ability to provide new treatment options, staff, and technology. This ultimately impacts the quality of care for patients. Even when breakthroughs in dialysis treatment become available, patients are not always informed about or granted access to them. This must change. One example is the limited adoption of new treatments like HIF-PH inhibitors, innovative drugs developed to treat anemia in dialysis patients. While these medications were expected to provide a more convenient alternative to traditional infusions, Medicare reimbursement concerns led to slow adoption, with some dialysis clinics unable or unwilling to offer them. There is also slow uptake of a new therapy to help reduce bloodstream infections for catheter patients.

DPC is committed to advocating for policies that realign dialysis payments to better serve patients. Fair and sustainable reimbursement ensures every patient receives the highest quality care possible. With a new administration in place, we have an opportunity to push for much-needed reforms, just as we have many times before during previous administrations of both political parties. President Trump has shown his commitment to kidney patients before by signing an Executive Order during his first term to promote home dialysis and transplantation. We will look to build on that progress and use the opportunities that new leadership in government provide, whether that is to improve dialysis funding, expand access to innovative treatments, or strengthen support for patients.

We will continue working to ensure policymakers recognize the urgent needs of the dialysis community. We must keep our voices strong, our advocacy focused, and our mission clear: improving the quality of life for all dialysis patients. With your continued support, we can make real progress in 2025 and beyond.

Thank you for being a part of this fight.

Sincerely,

Hrant Jamgochian, J.D., LL.M.
Chief Executive Officer, Dialysis Patient Citizens

Ask the Doctor

By Velma Scantlebury, MD, DPC Education Center Health Care Consultant

1. What is the impact of phosphorus on kidney patients?

For patients with kidney disease on dialysis, they are unable to remove excess phosphorus from the blood. This leads to high phosphorus levels, also known as hyperphosphatemia. Since dialysis does not remove phosphorus, it is important to limit foods high in phosphorus to avoid a build-up in various places in the body. Too much phosphorus results in the following:

> **After a kidney transplant, phosphorus levels can drop rapidly, often requiring patients to eat more phosphorus or take supplements to restore balance**

Bone and heart problems: Excess phosphorus causes your body to pull calcium out of your bones, making them weak and brittle. Phosphorus can also combine with calcium to result in damaging deposits in the blood vessels, in the heart, eyes, as well as in other organs. This results in significant heart disease, hardening of the arteries, and decreased blood flow to many areas in the body.

Kidney damage: High phosphorus levels can directly harm the kidneys and worsen existing kidney disease in patients with chronic kidney disease (CKD).

Increased risk of death: High phosphorus levels are an independent risk factor for death due to severe vessel damage.

> **High phosphorus levels are an independent risk factor for death due to severe vessel damage.**

2. What is the impact of phosphorus on transplant patients?

Once patients receive a new functioning kidney, they now have the ability to clear the phosphorus that has been stored in the body tissues, especially the skin. This may occur very quickly, leading to abnormally low phosphorus levels in the immediate period after the kidney transplant. Patients will often have to eat foods high in phosphorus to keep up with the high level of clearance of phosphorus from the body. This eventually stabilizes but many patients may need phosphorus supplements for a short period after the transplant.

Phosphorus: A Hidden Challenge in Dialysis

Natalie Zuniga,
DPC Board Vice President

I was diagnosed with End Stage Renal Disease (ESRD) – or kidney failure – soon after a heart attack seven years ago. Like many ESRD patients upon diagnosis, I immediately thought of my mortality and what my death would mean for my family. But I knew that kidney failure wasn't a death sentence.

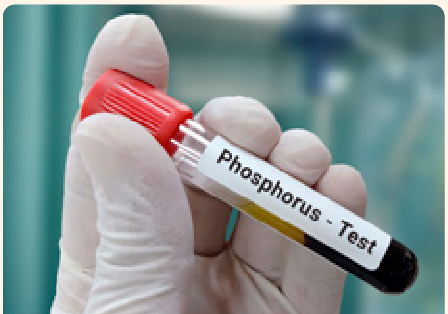
My husband, Eddie, had been on dialysis for five years when I was diagnosed with ESRD, so he gave me a sense of what life with kidney failure would mean. Today, we navigate dialysis treatment together, including the strict dietary restrictions and lifestyle changes it requires. One challenge I didn't anticipate was the difficulty of controlling my phosphorus levels. This oft overlooked but vital health metric can determine the future of a dialysis patient's health.

Phosphorus isn't something many people think about unless they're on dialysis. But for those of us with kidney failure, it's a big deal. When the kidneys fail, they can't filter excess phosphorus from the blood. High phosphorus levels can cause severe health issues, from itchy skin and ulcers to much worse—like the risk of needing amputations. For me, high phosphorus, also known as hyperphosphatemia, has been a constant battle. My phosphorus levels were consistently high, above 8, when the normal range is 5.5 or below. No matter how strictly I followed the renal diet, which meant giving up foods I loved, like beans and cheese, my phosphorus wouldn't budge.

Diet is only one part of managing phosphorus. I took phosphorus binders with every meal, which patients take to lower excess phosphorus levels. Yet, binders weren't enough. I continued to suffer the effects of high phosphorus, including low energy and brain fog. It was frustrating because my blood levels were great otherwise. Eddie and I ate the same foods, and while his phosphorus was under control, mine stayed high.

Every patient's body is different, which is why phosphorus control is a significant struggle for some and not for others. Thankfully, I learned about phosphorus blockers through the Dialysis Patient Citizens (DPC) Education Center. The DPC Education Center hosted a live discussion on **phosphorus management**, and one of the speakers talked about blockers, a newer medication that isn't as widely known. Unlike binders, phosphorus blockers prevent phosphorus from being absorbed into the bloodstream at all. I decided to try them, but there was a problem—insurance typically doesn't cover them.

I wasn't going to give up. I got a free month of phosphorus blockers to test them out. The results were almost immediate: my phosphorus levels dropped from 8 to 5.6 in that first month. I was thrilled. I took my results to the insurance company, and they finally agreed to cover the medication. Now, after two months on blockers, my phosphorus is down to 5.3, and I feel like a new person. My energy is back, and my mind is clearer than it's been in years.



It's incredible how much of a difference phosphorus control can make.

Most dialysis patients don't even know phosphorus blockers exist. Most dialysis patients don't know about many resources that could change their lives, which is why DPC Education Center's work is so important. They connect patients with the resources and information we need to take control of our health.

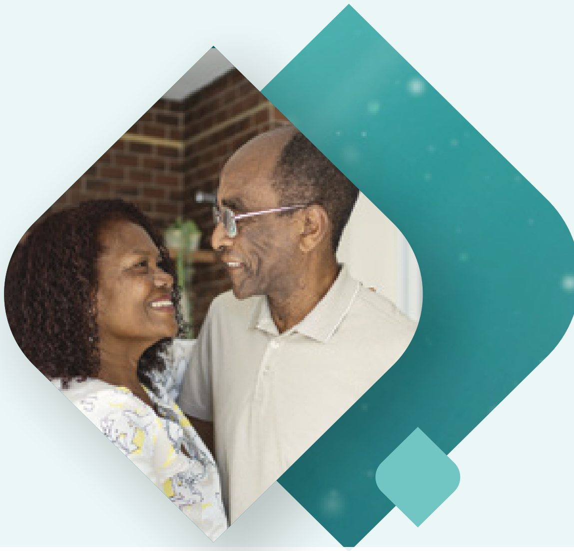
Managing phosphorus is a challenge, but we can overcome it with the right tools and support. For anyone struggling with high phosphorus, I encourage you to speak with your healthcare professionals, your fellow patients, and the DPC team. Educating ourselves through these conversations is the best way to improve our quality of life and face kidney failure with strength and hope.

Of course, having a supportive partner like Eddie by my side has made all the difference. We've been married for over 40 years, and while kidney failure has tested us, it has also brought us closer. Together, we're looking forward to our future. I'm even preparing for a kidney transplant, which will come with its own set of adjustments. Thanks to help from DPC and others, I'm thriving and ready for my next chapter.

Natalie's article was written by her a month before her passing. She was always willing to speak-up for patients and to help her fellow advocates. Her kindness and voice will be sorely missed.

Having trouble getting phosphorus to goal?

XPHOZAH®
(tenapanor) tablets



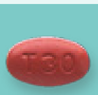
A different way to lower your phosphorus is here.

As add-on therapy for patients on dialysis in whom a phosphate binder does not work well:

- XPHOZAH can help reduce serum phosphorus in adults
- XPHOZAH is not a binder, it's a blocker
- XPHOZAH blocks phosphorus throughout the day when taken just before your first and last meal

Ask your healthcare provider about XPHOZAH.

One pill, twice a day.



actual size

Scan or visit XPHOZAH.com to learn more

INDICATION

XPH OZAH (tenapanor) 30 mg BID is a prescription medicine used to reduce serum phosphorus in adults with chronic kidney disease (CKD) on dialysis as add-on therapy when phosphate binders do not work well, or when phosphate binders cannot be tolerated.

IMPORTANT SAFETY INFORMATION

The most important information about XPHOZAH is:

- XPHOZAH may result in softer and/or more frequent bowel movements.
- Do not give XPHOZAH to children who are less than 6 years of age

Do not use XPHOZAH in:

- Children who are less than 6 years of age
- Patients who have a suspected bowel blockage

Before taking XPHOZAH, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant
- are breastfeeding or plan to breastfeed

Do not use XPHOZAH with stool softeners or laxatives. **Tell your doctor about all the medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

XPHOZAH can cause serious side effects, including:

Diarrhea is the most common side effect of XPHOZAH, and it can sometimes be severe. Call your doctor if you develop severe diarrhea.

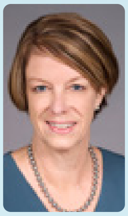
These are not all the possible side effects of XPHOZAH. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. You may also report side effects to www.fda.gov/medwatch.

Please see Brief Summary of the full Prescribing Information on the following pages.

ardelyx

The Importance of Immunizations

FOR PEOPLE WITH KIDNEY DISEASE



By Rebecca Schmidt, DO, Jeffrey Silberzweig, MD, Kristina Bryant, MD,
On Behalf of the American Society of Nephrology's Kidney Community Vaccination Collaborative

Introduction

Living with kidney disease presents unique health challenges, including an increased susceptibility to infections. Immunizations play a crucial role in protecting people with kidney disease, including those on dialysis or with a kidney transplant, from preventable diseases. This article will discuss the importance of vaccines in general and those protecting against respiratory illness specifically, the risks associated with not being vaccinated, and concerns related to misinformation on vaccination decisions.

Why Immunizations Are Crucial for People with Kidney Disease

People with chronic kidney disease (CKD) have weakened immune systems and thus, they are less able to fight off infections. Fortunately, vaccines provide additional protection against a number of different infections, such as influenza, hepatitis B, COVID-19, germs causing pneumonia and more recently, respiratory syncytial virus (RSV). The recent rise in rates of flu, COVID-19 and RSV underscore the importance of vaccination especially for patients with CKD requiring dialysis.

1. **Increased Risk of Infections**: People with CKD are more susceptible to severe complications from diseases that vaccines can prevent. People with CKD are more likely to develop COVID-19 and had higher rates of death and other complications than people without CKD during the height of the pandemic. Adults with CKD are also at higher risk for hospitalization from RSV infection.
2. **Preventing Severe Illness**: Vaccines help prevent severe illness, reduce the need for hospitalization, and are especially important in the fall when respiratory viral illnesses are circulating and can be particularly severe in people with CKD. In addition to flu and COVID, people with CKD are vulnerable to other respiratory illnesses such as pneumococcal pneumonia. Immunization can reduce the chances of developing pneumonia. New attention has been focused on RSV, which is being seen more in adults and has potential to cause serious illness particularly in people with CKD. The RSV vaccine can reduce the chances that people with kidney disease will be hospitalized with RSV infection.
3. **Protecting Against Non-Respiratory Diseases**: Vaccines like the hepatitis B are crucial for people with CKD, especially those on dialysis, as they are at higher risk of contracting

hepatitis B from blood transfusions and exposure while in the dialysis unit.

Risks of Not Being Vaccinated

The decision to forgo vaccination can have serious consequences for people with kidney disease.

1. **Higher Risk of Severe Illness**: Unvaccinated people with kidney disease are at a higher risk of contracting diseases that can lead to severe illness, hospitalization, or even death.
2. **Increased Healthcare Costs**: Treating preventable diseases can save on one's healthcare costs due to hospital stays, medications, and additional treatments.
3. **Impact on Quality of Life**: Frequent infections and their complications can significantly impact the quality of life for people with CKD by leading to prolonged recovery times and decreased overall well-being.

Recognizing Misinformation

Misinformation about vaccines can reduce confidence in vaccines or increase aversion to seeking vaccination, which is particularly dangerous for people with kidney diseases. Here are some common myths and the truths:

Myths:

1. **Vaccines are unsafe for people with CKD:** Vaccines are thoroughly tested for safety and efficacy. The benefits of vaccination far outweigh the risks, especially for immunocompromised individuals.
2. **Vaccines can cause the disease they are meant to prevent:** Vaccines contain inactivated (non-live) or weakened (live) forms of a virus which help the immune system recognize and fight the virus if exposed to it in the future. Non-live vaccines cannot cause disease they are designed to prevent. Live vaccines very rarely cause disease and are not given to *severely* immunocompromised individuals, such as those who have undergone kidney transplant.
3. **Natural immunity is better than vaccine-induced immunity:** While natural immunity can provide protection, it comes at the cost of suffering through the disease and its potential complications. Vaccines provide a safe and controlled way to develop immunity and strengthen the immune system. For diseases like COVID-19, immunization provides additional protection to people who have had prior COVID disease, reducing the risk of repeat infection.

Truths:

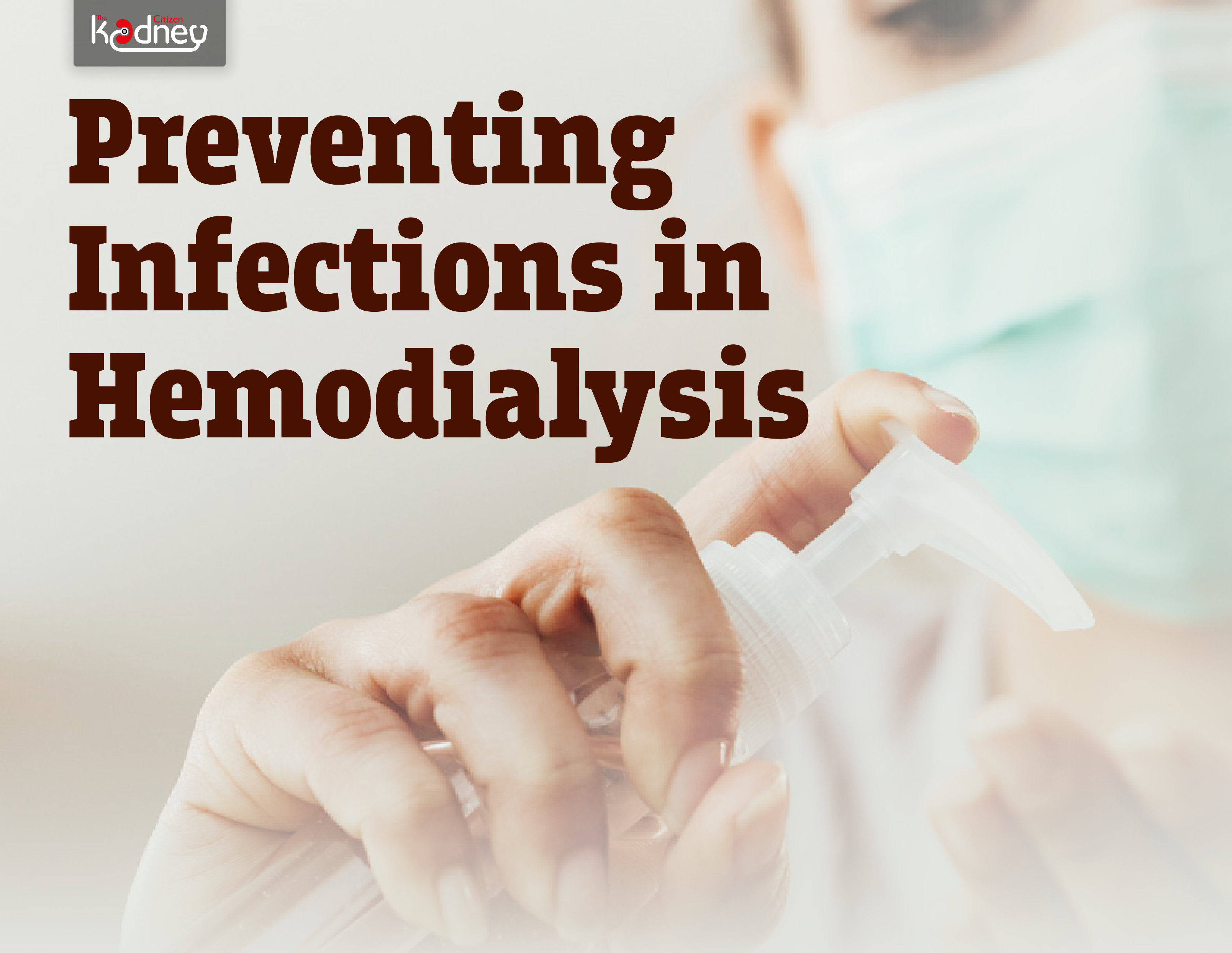
1. **Vaccines are thoroughly tested before receiving approval** from the US Food and Drug Administration and considered safe for people with CKD as recommended by the CDC.
2. **Side effects do happen but are usually minor and much less significant than the disease** against which people are vaccinated. Common side effects of vaccines include pain at the injection site, headaches, fatigue, and mild upper respiratory symptoms.
3. **It is safe to receive both the flu and COVID vaccines on the same day** as recommended by the CDC Using separate arms for each vaccine can help minimize pain at the injection site.
4. **The pandemic had an unprecedented impact on people with kidney disease;** almost half of people with CKD who were infected with COVID-19 died compared to about 5% of the general population. Among people with CKD on dialysis, so many died that for the first time in the 50-year history of the Medicare End Stage Renal Disease program, the total number of people on dialysis in the United States declined. Vaccination against COVID-19 reduces the chances of severe disease and death and may reduce the risk of developing long COVID.

Finding True Information

Seek out your doctor or the staff at your clinic or dialysis facility and ask them for information and resources about the safety and efficacy of vaccines.
Seek out trusted sources such as the American Society of Nephrology's **Kidney Community Vaccination Collaborative,** the **National Kidney Foundation** and the **CDC** for information about vaccinations.

Conclusion

Immunizations are a vital part of maintaining health and preventing serious infections for people with CKD. The risks of not being vaccinated far outweigh the risks for potential side effects of vaccines. It is essential to rely on accurate information from trusted resources when making decisions about vaccinations. By choosing to stay up to date with recommended vaccines, people with CKD can protect themselves and improve their quality of life.
If you have questions or concerns about vaccinations, please talk to your doctor or the nurse at your clinic or dialysis facility. They can provide personalized advice based on your specific health needs. Stay informed, stay protected, and take control of your health.



Preventing Infections in Hemodialysis

By Dr. Anil Agarwal,
Nephrologist

For patients undergoing hemodialysis, infection prevention is not just a recommendation, it's a necessity. Hemodialysis patients have a compromised immune system and face a heightened risk of infections, which can affect their lives in a multitude of ways.

Many suffer from bloodstream infections, which can lead to hospitalization and even life-threatening complications like sepsis. Catheter-related infections and skin infections near the vascular access site, also quite common, can put patients in the hospital as well. Any of these infections can delay hemodialysis patients' upcoming kidney transplant. Luckily, with education and vigilance, patients can use strategies to avoid many of these infections.

In my years as a nephrologist, I've seen how small, consistent efforts can dramatically improve patient outcomes. A simple infection prevention checklist can help patients stay on track. The checklist ought to include:

- Daily hygiene habits: washing hands before and after touching the access site, keeping the area clean and dry, looking for any redness or swelling that could indicate an infection, avoiding unnecessary contact with the catheter or fistula, protecting the access site during showers, and steering clear of public pools and hot tubs.
- Dietary habits: following a balanced kidney patient plan that focuses on patients' protein, potassium, and phosphorus levels helps maintain overall health and supports the immune system.
- Treatment habits: Attending all scheduled dialysis sessions, getting vaccinated against common infections, taking medications as prescribed, and promptly reporting any concerns to the care team further strengthen this approach.

One patient, Celina Medina, serves as a powerful example of why infection prevention is so critical. Diagnosed with kidney disease in childhood, she has endured multiple hospitalizations and two transplants. Throughout her journey, infections have been an ongoing challenge, particularly during her pregnancies when complications put both her and her children's health at risk.

"When I was in my childhood years and my teenage and young adult years, I was in and out of the hospital with infections, but luckily my mom was very careful. She was very meticulous about having everything disinfected. I was really kept in a bubble basically throughout my whole entire life," Celina said.

"I got married and I had my first child at 24," Celina said. "And because of the deterioration of my health, luckily my unborn child in the womb was actually keeping me moving forward with her kidneys. I had a very hard pregnancy – my daughter was born at only 31 weeks. And then I went into my first dialysis when my daughter was barely two years old."

Later, after having her second child, Celina started feeling sore in the area around her Central Venous Catheter (CVC) port. It was tender, but she didn't have a fever, so doctors thought she must have just irritated it somehow. A week after her peritoneal catheter was put in, Celina found herself in the hospital with an infection in her CVC. "I was rushed to the hospital. Mind you I was incoherent at this point. I did not know what was going on."

"Within three days, doctors were already giving me different medications, a little bit stronger to combat the infection, and within a week of staying in the hospital they started doing dialysis through my peritoneum and I went into surgery to have my CVC catheter port removed. It was then when they saw that there was so much scar tissue and it was so infected, that when they took it out they said there was pus everywhere. It was bad to the point where the doctors after my stay there at the hospital said, 'Unfortunately, if you ever go back on dialysis you will not be able to use that same area because it's pretty much damaged from that infection.'"

Ultimately, Celina went back on peritoneal dialysis, which lasted for 12 years, part of which she was also using a CVC. Fortunately she was able to avoid further infections and received her second transplant in May of 2019.

Throughout her experience enduring a series of health complications, Celina educated herself about how to avoid infections, implemented best practices into her daily routine, and she now lives a flourishing life. She understands firsthand how easily bacteria can spread and takes extra precautions in her daily life.

Celina said "It's about having that presence of mind to know that if I go swimming, if I go into a hot tub, what are the dangers going to be like for me? What's the probability of getting an infection?"

Celina's experience with infections and the resulting health challenges had a profound impact on her life and her family's life. However, she now manages her condition with confidence, and her discipline has allowed her to serve the homeless population of Orange County, California, while also encouraging people to do everything possible to prevent infections. "I'm always telling people, wash your hands up to your elbows. With the population that I do work with, I'm on the streets. I'm literally talking to the people that are laying on the floor underneath the bridges and I'm more susceptible to infections when it comes to that. I have my mask on, I have my glasses on, and I have my gloves."

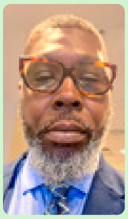
Celina is now a proud advocate for organ donation and a patient advocate for Dialysis Patient Citizens (DPC) whose story highlights the importance of preventing infections and the ability to lead a thriving life while keeping oneself safe. "I strongly suggest that my fellow dialysis patients discuss with their nephrologist how to best prevent catheter infections, as well as new technologies that are now available to reduce the risk of infection," Celina said. Nephrologists are now empowered to recommend new therapies to reduce the risk of bloodstream infections for their catheter patients.

Preventing infections requires a shared effort between patients and healthcare providers. Dialysis centers should uphold strict aseptic techniques, ensure staff receive ongoing infection control training, and encourage patients to speak up about any concerns. Patients, in turn, should feel empowered to take control of their own care by following best practices and maintaining open communication with their medical teams. They should discuss with their medical providers about all available methods of preventing infection that may be beneficial to them. The daily steps and a careful approach to infection prevention may seem small, but they can make a profound difference in protecting patients from serious complications.

DPC has a profound role to play in dialysis patient care. DPC's Education Center serves as a crucial resource for new dialysis patients who may not understand the ins-and-outs of their condition. With the help of DPC, more and more dialysis patients can rest assured that they're doing everything they can to recover and thrive.

Infection prevention is not just a medical issue—it's a commitment to long-term health and quality of life.

Patience and Strength
A Caregiver's Journey



By Christopher James,
DPC Patient Ambassador

Caring for a loved one with kidney failure requires confronting serious challenges, making significant sacrifices, and pushing through intense emotions.

My name is Christopher James, and for years I have been a kidney patient caregiver to multiple family members, including my wife, Niesha Neal. Through my experience, I've learned that fulfilling the role of a kidney patient caregiver comes down to patience, perseverance, and love.

My caregiving journey started with my brother, who began dialysis many years ago. With help from my background in biomedical technology, I took on the role of learning how to operate and maintain his dialysis machine. Later, my father developed kidney failure and required in-center treatment, which presented new challenges to his ongoing battle with dementia. Sitting with him during treatments to prevent his confusion and discomfort became a routine part of my life and my brother's life.

Then my wife Niesha was diagnosed with kidney failure. Managing her care at home while raising our children, working, and maintaining daily responsibilities was overwhelming at times. Some days were manageable, but others were incredibly difficult. Dialysis drained her physically and emotionally, and as her caregiver, I often felt helpless. There were moments when she wanted to give up, exhausted by the constant toll of dialysis treatment.

Her journey to a transplant was long and full of disappointments. Over five years, she received six calls for potentially viable kidneys that never resulted in a transplant. Each time, her hope was crushed a little more.

On one bittersweet day, we got news that changed everything. That day, my mother passed away from her battle with Alzheimer's. On that very same day, Niesha was told that a kidney and pancreas were available for her. The emotional weight of joy for Niesha and sorrow for my mother was difficult, but ultimately, Niesha's successful transplant marked a new beginning for us.

Our journey brought us to Dialysis Patient Citizens (DPC) to advocate for better support for kidney patients and their caregivers. One of the biggest challenges many families face is the gap in insurance coverage between diagnosis and when Medicare or Medicaid benefits begin. I saw firsthand how this financial burden affected my brother, who lost his insurance after his kidney failure diagnosis, leaving him struggling to pay his bills. I even lost my job due to the amount of time caring for Niesha, presenting complex financial difficulties. We must push for policies that ensure all patients receive the care they need without added financial challenges.

To fellow caregivers, my message is simple: You are not alone. The road can feel isolating, but support exists. Seek out caregiver groups, connect with medical professionals, and take care of yourself. I found that even brief moments of meditation helped me reset when the stress felt too heavy. Accepting that things often won't always go as planned made a big difference in my mental health.

Most importantly, remember that your efforts matter. You are a lifeline for your loved one.

Today, Niesha and I continue to advocate for kidney patients, sharing our story to help others navigate their own journeys. Caregiving is never easy, but through support and advocacy, you can make a difference!

A Faithful Kidney Patient Caregiver's Journey

By Sheree Stephens,
DPC Patient Ambassador

I would describe being a kidney patient caregiver to my husband as inspiring, beautiful, and life changing. Ken has fought kidney failure for years, and I've stood beside him every step of the way. The journey can be, at times, stressful and tiring but with strong communication and a strong relationship with God, the journey is not nearly as overwhelming.

When we met in 2010, he told me upfront his kidneys were failing. I heard him, but love doesn't calculate risks. We built a life together, knowing challenges would come. In 2016, they did. Ken started peritoneal dialysis, and our world changed.

Peritoneal dialysis impacted our lives, but Ken managed treatments independently. He managed his treatments and care while I kept his supplies in order, assisted with monitoring his health, and, most importantly, lifted his spirits. I moved his dialysis fluids in and out of our home, knowing a hernia could set him back. I sterilized every treatment space to prevent infections. We continued to travel, since we didn't want dialysis to prevent us from living life to the fullest. Thus, we brought his dialysis machine wherever we traveled. I bleached every hotel showerhead and kept every surface disinfected. We wanted to ensure our lives had as little impact from Ken's disease as possible. We were at lacrosse games, school functions, were band booster members, and very involved in our church and community. When we traveled, we traveled by car, plane, and train. Ken's dialysis machine saw Florida to Hawaii and south Texas to Chicago. Ken is a fighter and warrior, and I was right there with him.

After seven years, his body couldn't handle peritoneal dialysis anymore. The switch to home hemodialysis changed our routine, but not our resolve. We learned every step of his treatment. When we completed training, we moved treatments into our home. I started my workday during treatments most days then went into work once treatments were complete. We learned to balance careers, treatment sessions, and living life. We traveled with home hemodialysis as well. Coordination of supplies were a little more involved but easily became our practice. We traveled by plane and RV with our home hemodialysis set up. We wanted to ensure Ken received the best care possible no matter our location.

I learned valuable lessons along this journey and one important one is when to step back. Dialysis is a vulnerable time. A patient sits, exhausted, drained, sometimes frustrated. That time became sacred in our home. No big decisions, no stressful conversations. If stressful family, friend, or work conversations needed to be had, those happened after his treatments were complete and once he had time to recuperate post treatment. Caregiving isn't just about medical support. It's about protecting their peace. I found that protecting his peace and supporting him really was my primary goal. The Lord has protection over our journey. We just stand in the space of doing what the healthcare team trains you to do, peace, support, and grace; the rest will follow.

Caregiving forces you to see what really matters. We never wasted time sweating the small stuff. We cherished every moment and still do. We learned to love the small things: delicious meals, warm laughter, the feeling of holding hands when words weren't enough.

Most importantly, God gave us the Grace to get through it. I believe He led us to Dialysis Patient Citizens (DPC) as well.

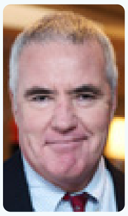
DPC's advocacy allowed us to channel our energies to fight for better dialysis care—not just for Ken, but for all dialysis patients. Speaking with legislators and sharing our story became part of our mission.

DPC gave us a platform to tell lawmakers what dialysis patients face every day. Insurance gaps, lack of access to advanced treatments, and workforce shortages. These aren't abstract issues. Rather, they're real struggles that dialysis patients endure. We need to fight to protect them.

Ken received his transplant in August 2024, which was a blessing. Nevertheless, it didn't feel like the end of the battle, the journey of End Stage Renal Disease never ends. The recovery brought its own challenges. Yet, the support we received from DPC reminded me that we are never alone. No caregiver is.

To caregivers out there, know this: you will get through the hardest days. Find a community. Set boundaries. Protect their peace. And most of all, hold on to your Faith.

Why Medicare's Payment System Keeps New Dialysis Drugs from Reaching Patients



By Jackson Williams,
DPC Vice President of Public Policy

Payment bundling is a technique Medicare uses to increase efficiency and reduce low-value care during a treatment episode. Congress adopted a payment bundle for dialysis a decade ago and for several years it worked well. But trade-offs are inherent in bundles and there is always potential for a negative impact on consumers. This negative experience has arrived for dialysis patients in the form of non—prescribing of new drugs. Patients are missing out on improvements to their health and quality of life.

A bundled payment sets a maximum price for all the items and services involved in a treatment or episode. When those items can no longer be billed separately, they can't serve as additional profit centers for providers, nor can providers be indifferent to amounts paid to other providers or suppliers. The provider is incentivized to organize care efficiently and minimize their costs because it keeps the difference between its costs and Medicare's price.

Patients can benefit when potentially dangerous, separately billable items are no longer provided. Dialysis services were bundled because when epo was billed separately, some dialysis clinics provided more than was necessary. Bundling can also reduce unnecessary scans that needlessly expose patients to radiation.

But by bluntly changing financial incentives to discourage provision of ancillary items, bundles don't necessarily distinguish between wasteful or dangerous items and items that are necessary for patients. When expensive new items are not paid for separately, the provider—in this case, the dialysis clinic—is likely to lose money and become unprofitable if it offers the items on an unrealistic budget.

The problem with the ESRD bundle is that what is efficient doesn't always match the interests of the patient. The ESRD provider, while paid per treatment, is expected to quarterback care longitudinally, from incidence to transplant or end-of-life, to include ongoing education, dietary advice, anemia, phosphorus control, and many other aspects of kidney failure. New renal products that provide quality-of-life gains to patients and/or efficiencies to Medicare expenditures outside of dialysis expenditures represent only *costs* to the dialysis provider.

Medicare tried to address this problem with what it calls a Transitional Drug Add-on Payment Adjustment (TDAPA) for new drugs for dialysis patients. It pays the cost of a new drug on an individual patient basis for two years, and at the end of two years adds up the money spent across patients who received the drug and then divides it across *all* dialysis patients to modestly increase the regular payment.

This method could work for inexpensive drugs that all patients get. But it doesn't work for expensive drugs that only a smaller number of patients get. Complicating things further is that unless every dialysis provider offers the new drug to patients using identical prescribing guidelines, some providers will be financial winners and losers when the two-year period ends. Under these circumstances, the rational reaction for providers and doctors is to not adopt the new drug.

The typical prescribing scenario in Medicare is that doctors have no disincentive to prescribe and may be incentivized to overprescribe. When prescriptions are paid for by a Part D prescription drug plan (PDP), PDPs can use formularies or prior authorization to restrict expensive drugs. In such cases, doctors act as advocates for their patients in obtaining the drug, and plans are the entity incentivized to contain costs.

The ESRD bundle replaces the traditional doctor/patient relationship with a new one—the nephrologist, usually in a joint venture with the dialysis clinic and a gatekeeper incentivized to keep utilization of bundled drugs low, and the Medicare program, which is primarily interested in minimizing ESRD expenditures. The patient is removed from the equation, because he or she is never informed about the availability of new drugs by nephrologists, whose motivation to act for patients is compromised.

Medicare's temporary payment, instead of mitigating the perverse incentives and uncertainties inherent in a bundling arrangement, instead exacerbates them. This has resulted in bleak prospects for new drugs being developed for dialysis patients:

- Cara Therapeutics has abandoned its renal activities after the failed launch of Korsuva and may be heading for bankruptcy. This means patients with pruritis have no access to an effective treatment for that condition. Empirical research has found a prevalence of moderate to severe pruritis among dialysis patients of 33 percent, but Korsuva has been dispensed to fewer than one percent of patients.
- Parsabiv is a new calcimimetic. During the 2019-2020 period, when a TDAPA add-on payment was made, 5,105 of 34,924 patients on dialysis (14.2%) received Parsabiv each month, according to a study by Stuart M. Sprague of NorthShore University HealthSystem. After January 2021 when the temporary payment ended, only 217 of those patients (0.7%) were receiving Parsabiv each month. Mean monthly PTH values increased from 483 pg/mL before the policy change to 544 pg/mL after the policy change. Among the 3,560 patients who discontinued Parsabiv when the payment policy changed in January 2021, mean monthly PTH increased from 579 to 745 pg/mL.
- GSK recently filed with the FDA to remove Jesduvroq, an oral HIF-PHI, from the market due to the inadequate TDAPA and post-TDAPA reimbursement, meaning one fewer option for patients who don't respond to ESAs.
- Ardelyx, manufacturer of the drug Xphozah, has filed a lawsuit against CMS rather than accepting TDAPA with its perverse dynamics that all but preclude profitability. This is a blow to patients with inadequate response to phosphate binders or who are intolerant of any dose of phosphate binder therapy.

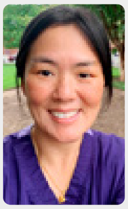
These are products on which many millions of dollars were invested to improve kidney care. This negative experience means venture capital is unlikely to make such investments in the future.

DefenCath, CorMedix's catheter lock solution, started its TDAPA period on July 1. This drug has promise to reduce infections in dialysis patients. There remains uncertainty about its uptake, given that costs are borne by dialysis organizations while the benefits—reduced infections and hospitalizations—accrue mostly to patients and the Medicare Trust Fund.

Akebia's Vafseo, an oral HIF-PHI to treat anemia in dialysis patients, started its TDAPA period in January 2025 after being approved several months ago. This drug could reduce transfusions for patients who don't respond to ESAs, but again, that is a benefit to patients and to Medicare, not to the provider. Unfortunately, there appear to be no more new innovations in the ESRD drug pipeline.

DPC believes that drug manufacturers must be compensated in line with the value they offer to patients and the Medicare system, and providers should be held harmless when they do the right thing. This means that for those expensive products needed by a minority of patients, the only way to guarantee access will be individual-level reimbursement in full, not fractional reimbursement across the entire population of patients. DPC is working with dialysis providers, nephrologists, and drug manufacturers through a broad coalition, Kidney Care Partners, to pass legislation to fix this problem.

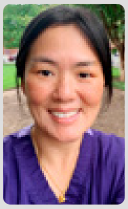
Kidney-Friendly Recipes



Thanks to Fanny Sung Whelan, MS, RDN, LDN, a member of the **Ed Center Advisory Council** and a registered dietitian who works with people with all stages of kidney disease, for providing us with this great kidney-friendly recipe* to kick off summer! This **recipe** was submitted by a patient to **Dialysis Clinic, Inc. (DCI)** for inclusion in their **Kidney Cooking** cookbooks.

Thanks to María E. Rodríguez, MS, RD, CSR, LND for providing us with the Spanish translation of this recipe! María is a registered dietitian and board-certified renal nutrition specialist with 16 years of experience in the kidney space. She lives in Puerto Rico and owns a virtual private practice where she works with Spanish-speaking adults who live with CKD to help them slow kidney disease progression.

**Always check with your nutritionist before incorporating new foods or recipes into your diet to make it is right for you.*



Gracias a Fanny Sung Whelan, MS, RDN, LDN, miembro del Consejo Asesor del Centro de Ed y dietista registrada que trabaja con personas en todas las etapas de la enfermedad renal, por brindarnos esta excelente receta renal* para comenzar el verano. Esta receta fue enviada por un paciente a Dialysis Clinic, Inc. (DCI) para su inclusión en sus libros de cocina “Cocina Renal”.

Gracias a María E. Rodríguez, MS, RD, CSR, LND, por proporcionarnos la traducción al español de esta receta. María es dietista registrada y especialista en nutrición renal certificada por la junta con 16 años de experiencia en el área renal. Reside en Puerto Rico y tiene una consulta privada virtual donde trabaja con adultos hispanohablantes que viven con ERC para ayudarlos a retrasar la progresión de la enfermedad renal.

**Consulte siempre con su nutricionista antes de incorporar nuevos alimentos o recetas a su dieta para asegurarse de que sean adecuados para usted.*

Shrimp & Grits

This recipe was submitted by Arnella Chatman for the DCI Kidney Cookbook

Ingredients
- Makes 4 Servings
- 1 c. stone ground white grits
- 2 T. unsalted butter
- 1/2 bunch small shallots, chopped
- 1/2 c. corn kernels
- 1 T. vegetable oil
- 1 pinch red pepper flakes (optional)
- 1/2 c. chopped red bell pepper
- 1 c. green peas
- 3/4 lbs. shrimp, peeled and deveined

Instructions

In a large pot, bring 3 cups of water to a boil. Add grits, lower heat to a simmer, cover and cook for 20 minutes, stirring occasionally. When grits are thickened yet creamy, remove from heat and stir in 1 T. of butter. Cover to keep warm. In a large skillet over medium heat, sauté shallots and corn in 1 T. of butter and oil. Add red pepper flakes if desired. Cook until corn is browned (about 2 minutes). Add bell pepper and peas. Cook for 2 minutes. Add a small amount of butter if skillet is dry, raise heat to medium to high and add shrimp. Sauté until cooked thoroughly about 1 minute per side. Stir and remove from heat. Spoon grits into bowls; top with shrimp and vegetable mixture.

Nutrition Facts (Per Serving)
- Calories: 220
- Sodium: 487 mg
- Potassium: 321 mg
- Phosphorus: 240 mg
- Protein: 23 g

Camarones con Sémola de Maíz

Receta enviada por Arnella Chatman para el DCI Kidney Cookbook

Tiempo de preparación: 20 min
Tiempo de cocción: 40 min
Tiempo total: 1 hora
Porciones: 4

Ingredientes:
- 1 taza sémola de maíz blanca molida gruesa
- 2 cucharadas mantequilla sin sal
- ½ manojo de chalotes pequeños, picados
- ½ taza maíz
- 1 cucharada aceite vegetal
- 1 pizca hojuelas de pimiento rojo (opcional)
- ½ taza pimiento rojo picado
- 1 taza guisantes verdes
- ¾ libra camarones, pelados y desvenados

Instrucciones:

En una olla grande, lleve 3 tazas de agua a ebullición. Agregue la sémola de maíz, reduzca a fuego bajo, cubra y cocine durante 20 minutos, revolviendo ocasionalmente. Cuando la sémola esté espesa pero cremosa, retire del fuego y mezcle con 1 cucharada de mantequilla. Cubra para mantener caliente. En un sartén grande a fuego medio, saltee los chalotes y el maíz con 1 cucharada de mantequilla y aceite. Agregue las hojuelas de pimiento rojo si deseas un toque picante. Cocine hasta que el maíz esté dorado (aproximadamente 2 minutos). Añada el pimiento rojo y los guisantes. Cocine por 2 minutos más. Si el sartén está seco, agregue un poco más de mantequilla, suba el fuego a medio-alto y añada los camarones. Saltee hasta que estén bien cocidos, aproximadamente 1 minuto por cada lado. Mezcle todo y retire del fuego. Sirva la sémola de maíz en platos y coloque encima la mezcla de camarones y vegetales.

Información Nutricional (por porción):

Calorías: 220
Potasio: 321 mg
Sodio: 487 mg
Fósforo: 240 mg
Proteína: 23 g

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DPC Kidney Chat

Connecting by phone with other kidney patients and their families

The DPC Kidney Chat is a unique program that offers real time support, hope, and education to chronic kidney disease (CKD) patients at all stages of the illness, as well as support for their family and friends. It can be helpful for those adjusting to kidney disease to:

1. Have someone to listen to them
2. Gain confidence in living with kidney disease
3. Feel more in control of their life
4. Provide fellowship and community for those on home dialysis
5. Gain tips and encouragement from both someone who has personal experience and from a healthcare professional.

This program is a telephone group experience with two facilitators: a person living with CKD and a healthcare professional. The program is open to any person living with kidney disease and their family members who have a telephone. It provides a safe place to discuss aspects of living with kidney disease. The group meets on the second Tuesday of the month at 2:00 pm Eastern for one hour.

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Join the call: Dial: 866-230-9002 Enter Meeting Code: 420 835 078#

Learn more and RSVP at www.dpcedcenter.org

The Citizen Kidney
A publication of Dialysis Patient Citizens (DPC) Education Center

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issue number 20 *The DPC Education Center would like to give special thanks to Ardelyx and CorMedix for their generous contribution that helped to make this publication possible.*