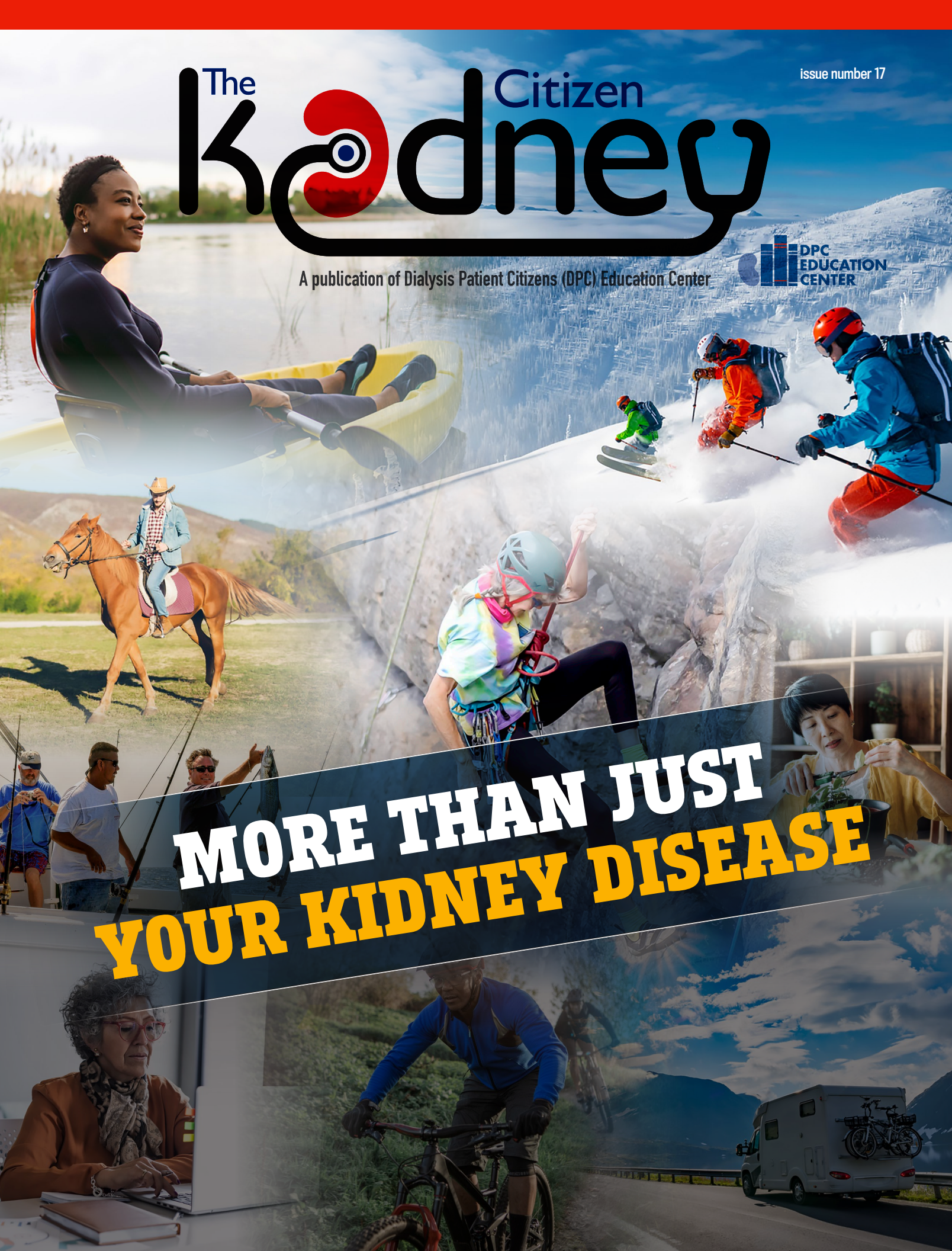


The Citizen Kadney

A publication of Dialysis Patient Citizens (DPC) Education Center



**MORE THAN JUST
YOUR KIDNEY DISEASE**

President's Message

CEO's Message



Greetings DPC Community. We hope you enjoy this issue of the Kidney Citizen. Our goal was to both inform and inspire. So, in addition to articles designed to further empower you to stay healthy, we added stories about patients who are not letting kidney disease get in the way of them living their best lives. We hope you will enjoy

these messages of hope and apply their tips and positive approach as you look to take on the challenges in your life.

At the DPC Education Center we are finding new ways to meet you where you are, rather than just encouraging patients to come to us. You may have noticed that we recently transformed our social media presence. We just launched a new [forum \(https://www.facebook.com/groups/dpcedcenter/\)](https://www.facebook.com/groups/dpcedcenter/) that you can join to engage with other patients, share helpful information, and speak about your own experiences with kidney disease.

There, you will also find information about new ways to engage with DPC as an advocate and access helpful resources regarding our upcoming events. We also just held our first Instagram Live discussion with our new Healthcare Consultant Dr. Velma Scantlebury. You can watch a recording on any of our social media platforms.

We also encourage you to join us in the months ahead for more Facebook and Instagram Live sessions to receive helpful information and answer your questions in real time. This way, you can reach us no matter where you are. Please "like" our page and comment, so that we will can better engage with you on-line.

We aren't going to stop there, however. Over the coming months, we are excited to share all of the new ways we will be working to reach you where you are. Our mission has always been to educate kidney patients and give them a voice, and these initiatives will help us to live up to that mission. To that end we will continue our newly launched Kidney Chat, a monthly call that is confidential and via telephone only. This is a wonderful opportunity for patients, family, and friends to meet other people navigating life with kidney disease, get helpful tips, and find encouragement from those who understand what you're going through.

As we look ahead to the summer months, we are excited to stay in touch, learn about what each of you is experiencing, and continue advocating side-by-side for policies that help patients and families affected by kidney disease. If you find yourself needing assistance, please do not hesitate to get in touch with us.

Merida Bourjolly,
President of DPC Education Center Board of Directors



There is a saying that "nothing in life is constant except change." COVID-19 has perhaps taken this statement to a whole new level. Whether we like it or not, things are different – how we work, learn, shop, do business, communicate, etc. Our challenge remains, how do we grow and evolve as individuals and as an organization.

While some are afraid of change, at Dialysis Patient Citizens (DPC) Education Center, we do our best to embrace it. In fact, innovation and continuous improvement remain a key part of our "core values."

While we remain committed to our mission of empowering kidney disease patients, we are constantly looking for new ways to increase our impact. We are now using social media more than ever to reach patients. In fact, we changed our Facebook page into a patient forum, to help increase our dialogue with you. We are also reworking the educational offerings on our website, while making it easier for you to find what you are looking for. The best news is that we are only getting started. Earlier this year, we added two dynamic and talented members to our team, to further bolster our educational efforts. We are thrilled to have Nancy Scott serve as our Education Project Manager and Dr. Velma Scantlebury as our Health Care Consultant.

Nancy Scott is a longtime ESRD patient and transplant recipient, who has been involved with DPC for many years. She has extensive experience as an advocate for the kidney disease community, having attended many of our advocacy days on Capitol Hill. Nancy also previously served as the Board President of the DPC Education Center. We are thrilled to add Nancy's expertise to our staff and look forward to all she will help us accomplish on behalf of the patients we serve.

Our new Health Care Consultant, Dr. Velma Scantlebury, is the first African-American female transplant surgeon in the United States. Dr. Scantlebury served as a kidney surgeon for 40 years, dedicating her life to educating and raising awareness for the health disparities people in the Black community face from kidney disease. Dr. Scantlebury is a trailblazer for the medical community as well as a role model for women and the African-American community alike, and we are thrilled to have her guidance at Dialysis Patient Citizens Education Center.

As all of us continue to adapt in the COVID-19 era, our commitment to you (our members) will not waiver. That said we will continue to look for new opportunities to serve you better, to evolve how we do things, and to make sure that our work remains both relevant and impactful. As an organization run by patients for patients, we have no choice but "to do more."

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

The DPC Education Center is Pleased to Welcome

Velma Scantlebury, MD, TO THE TEAM!

Velma Scantlebury, MD, the first African-American female transplant surgeon in the United States, has joined Dialysis Patient Citizens as a healthcare consultant.

Dr. Scantlebury served as a kidney surgeon for over 30 years, dedicating her life's work to educating and raising awareness for the health disparities people in the Black community face from kidney disease. Born in Barbados, Dr. Scantlebury's family moved to New York City when she was 15. She attended Long Island University on a full academic scholarship, obtaining a biology degree with a pre-med focus. Dr. Scantlebury then earned her medical degree from Columbia University, completed her residency in general surgery at Harlem Hospital, and finished her clinical fellowship at the University of Pittsburgh's Transplantation Institute.

Today, Dr. Scantlebury is an esteemed lecturer and humanitarian, still working to eliminate health disparities and building the next generation of workforce professionals at the Delaware Health Equity Coalition in Wilmington, Delaware.

Dr. Scantlebury is both a trailblazer for the medical community and a role model for women and the African-American community alike, and we are thrilled to have her guidance as our newest healthcare consultant at Dialysis Patient Citizens.





Ask the Doctor



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

- 1. Four hours is too long for me to sit in dialysis. Do I have to attend every treatment?**

Answer: Think of dialysis as being the only way to get the toxins out of your body from the food that you consume everyday - three times a day. When you lose kidney function and are on dialysis, you are usually then only cleansing your body every other day. Those toxins will build up and can cause your body to deteriorate over time.

Missing dialysis is harmful to your body. It causes toxins and water that cannot pass out to sit in your system, which jeopardizes your heart and puts you at risk for worsening complications.

It is very important that you maintain your dialysis schedule as recommended by your healthcare professionals. If you are unable to tolerate the 4 hours, talk to your doctors about possible options that might work better for you. Dialysis is important to maintaining your health.



You may want to consider home dialysis, which will allow you to cleanse your body daily.

- 2. I am 50 years old—will I be on dialysis forever?**

The only option to replace dialysis is a kidney transplant. Unless your kidney disease is reversible, then dialysis and transplantation are the only options to restore your body to better health. Dialysis cannot eliminate all the toxins,

but it is the most frequent form of kidney replacement therapy for patients with end stage renal disease.

- 3. I recently changed jobs and my insurance does not cover my transplant medications. Can I take my medicine every other day?**

Not taking your medications puts your kidney transplant at risk for rejection. You need your medications in your system at all times, as they block your immune system from attacking your kidney. When you skip doses of your medication, you leave a large amount of time for your immune system to attack the kidney. I would recommend talking with your transplant pharmacist about other options for medications that might be covered by your insurance. There may be other alternatives that your insurance will cover. This is critical.

- 4. I had a transplant a year ago. I skip lab tests often. Is it necessary to get labs consistently?**

Since you are only one year out, it is important to get labs done routinely, as rejection can occur without any symptoms. The lab work is often the first signal that your transplant is in jeopardy. When your doctor feels it is safe to increase the time interval between labs, they will do that.



8 Ways to Be a Safe Patient

When you have surgery, receive dialysis, or visit your doctor, you deserve safe care. Everyone plays a role in patient safety and quality health care. CDC and its partners provide expertise, data, and programs for safe health care to support public health, healthcare workers, patients, and caregivers.

How Can I Be a Safe Patient?

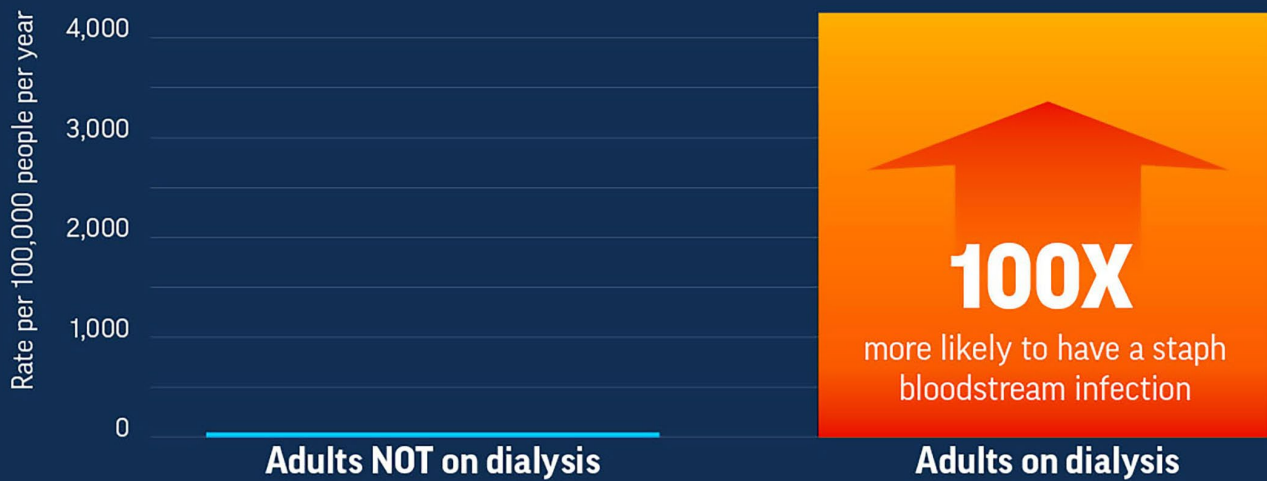
- **Speak up.** Talk to your healthcare provider about any questions or worries. Ask what they're doing to protect you from infections.
- **Keep hands clean.** Make sure everyone, including friends and family, cleans their hands before touching you. If you don't see your healthcare providers clean their hands, ask them to do so.
- **Be Antibiotics Aware.** Antibiotics only treat bacterial infections—they don't work for viruses like the ones that cause colds, flu, or COVID-19. Ask your healthcare professional about the best way to feel better while your body fights off the virus.
- **If you need antibiotics,** make sure to take them exactly as prescribed and do not skip doses. Talk with your healthcare professional if you develop any side effects, especially severe diarrhea, since that could be a *C. diff* infection, which needs to be treated immediately.
- **Staying in a nursing home or assisted living facility?** As a resident, you may be at increased risk for infections. Learn more about ways to stay safe.
- **Act fast if you suspect sepsis.** Infections can put you or your loved ones at risk for a life-threatening condition called sepsis. Anyone can get an infection, and almost any infection, including COVID-19, can lead to sepsis. Learn how you and your loved ones can take specific steps to reduce your risk of sepsis and ACT FAST if you suspect it.

Together, We Can Improve Patient Safety

Learn more from CDC and spread the word about how to be a safe patient: <https://www.cdc.gov/PatientSafety>



Staph Bloodstream Infections



Vital^{CDC}signs™

Source: February 2023 Vital Signs



CS335922

**Black and
Hispanic Patients
on Dialysis Have
Higher Rates of
Staph Bloodstream
Infections**

Actions to Reduce Inequities Can Save Lives

CDC Newsroom Media Statement –
Originally published February 6, 2023
Contact: Media Relations, (404) 639-3286

Adults on dialysis treatment for end-stage kidney disease were 100 times more likely to have a *Staphylococcus aureus* (staph) bloodstream infection than adults not on dialysis during 2017–2020, according to a new *Vital Signs* report released today by the Centers for Disease Control and Prevention (CDC).

More than half of people in the U.S. receiving dialysis belong to a racial or ethnic minority group—about 1 in every 3 people receiving dialysis is Black and 1 in every 5 is Hispanic. CDC data found patients on dialysis in these groups have higher rates of staph bloodstream infections than White patients on dialysis.

Dialysis treatment, although necessary and lifesaving, comes with risks. Healthcare providers use needles or catheters to connect a patient to a dialysis machine, and germs, like staph, can get into a patient's bloodstream. Staph bloodstream infections can be serious and even deadly. Some infections are resistant to some of the most common antibiotics used to treat them, making the drugs ineffective.

CDC data confirmed one of the key ways healthcare providers can reduce the risk of infection is by using lower-risk alternatives, such as fistulas and grafts, to replace central venous catheters to connect patients' blood circulation to dialysis machines for treatment.

Hispanic patients on dialysis had a 40% higher risk of staph bloodstream infections than White patients on dialysis between 2017 and 2020. Other challenges for many patients on dialysis include:

- Lack of access to preventive care for conditions like diabetes and high blood pressure, which increase the risk of developing end-stage kidney disease.
- Lack of patient education about treatment options for end-stage kidney disease.
- Extended use of a central venous catheter to connect a patient's blood

circulation to a dialysis machine for treatment (also known as a vascular access type). Catheters have the highest risk of infection among all vascular access types.

- Socioeconomic factors, including poverty, household crowding, and lower education levels.

"Preventing staph bloodstream infections begins by detecting chronic kidney disease in its early stages to prevent or delay the need for dialysis," said CDC Chief Medical Officer Debra Houry, M.D., M.P.H. "Healthcare providers can promote preventative practices, including methods to manage diabetes and high blood pressure, as well as providing education on treatment options among all patients and particularly those at greatest risk, to slow the progression of chronic kidney disease."

CDC researchers used data from the 2020 National Healthcare Safety Network (NHSN) and the 2017–2020 Emerging Infections Program (EIP) to describe bloodstream infections among dialysis patients. To examine associations with race, ethnicity, and social determinants of health, these data were linked to population-based data sources (CDC/ATSDR's Social Vulnerability Index, United States Renal Data System, U.S. Census).

Key findings:

- In 2020, 4,840 dialysis facilities reported 14,822 bloodstream infections to NHSN; 34% were due to staph.
- In both NHSN and EIP systems, vascular access via central venous catheter was strongly associated with staph bloodstream infection.
- Among seven EIP sites in 2017–2020:
 - The staph bloodstream infection rate was 100 times higher in dialysis patients than adults not on dialysis.
 - Among patients on dialysis, staph bloodstream infection rates were highest in Black and Hispanic patients.
 - Adjusting for state of residence, age, sex, and vascular access type, the staph bloodstream infection risk was highest in Hispanic patients and

patients 18–49 years old. People in areas with higher poverty, household crowding, and lower education had more staph bloodstream infections.

The good news is that bloodstream infections in patients on dialysis have decreased since 2014 with the widespread use of proven practices to prevent and control infections

"Dialysis-associated bloodstream infections are preventable—not inevitable," said Shannon Novosad, M.D., M.P.H., Dialysis Safety Team Lead in CDC's Division of Healthcare Quality Promotion. "Our data show that use of a central venous catheter as a vascular access type had six times higher risk for staph bloodstream infections when compared to the lowest-risk access, a fistula. Prevention efforts that equitably promote lower-risk vascular access types and continued use of infection prevention and control best practices can save lives."

The good news is that bloodstream infections in patients on dialysis have decreased since 2014 with the widespread use of proven practices to prevent and control infections. Preventing infections among patients receiving dialysis requires a broad and equitable approach to the prevention and care of kidney disease for people from all racial, ethnic, and socioeconomic groups.

For more information about this report, go to www.cdc.gov/vitalsigns.

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

CDC works 24/7 protecting America's health, safety and security. Whether diseases start at home or abroad, are curable or preventable, chronic or acute, or from human activity or deliberate attack, CDC responds to America's most pressing health threats. CDC is headquartered in Atlanta and has experts located throughout the United States and the world.



For Mike Guffey, Working Was Key to Staying Positive



When Mike Guffey began dialysis treatments in 2008, one of his top priorities was to ensure he had a reason to keep moving forward, something to look forward to when he

got out of bed which would allow him to push through his treatment regimen.

For him, that meant returning to work as quickly as he could after starting his treatments, especially given how quickly he crashed into life on dialysis.

Normally based in Kansas City, Mike was working temporarily as a project manager in Colorado when he noticed something was off. He went to the doctors thinking he had altitude sickness, and the doctors told him it was likely either that or the flu. They prescribed antibiotics to help the sickness, but he only started feeling worse.

Shortly after, he went to visit his parents in Arizona but had trouble getting on and off the plane by himself. His parents told him to go to a nearby clinic, where he was told he had to go to the emergency room immediately.

When he got to the E.R., they told him he shouldn't even be standing up in his condition, let alone driving. He was admitted to the hospital immediately, and the care he received over the next 24 hours was critical in keeping him alive.

Before he knew it, he was diagnosed with renal failure and admitted to the intensive care unit. He had no family history of kidney disease, no comorbidities to speak of; he was just dropped into life with kidney disease. He had to reorient his life, figuring out ways to work dialysis treatments into his weekly routine.

After about three weeks, he was able to return to the job he had been working

in for 20 years and resume his previous schedule. Now back in Kansas City, he went into work full-time, coming in slightly earlier on the three days each week that he had to leave for the dialysis clinic at 4:30. Having four-and-a-half hour treatments after work wasn't easy – he was often one of the last few people there at night – but he was able to manage his recovery time and continue working in a job he loved.

His treatments weren't enough to keep him from doing his best to help everyone he could, either. When a tornado struck Joplin, Missouri in 2011, it was important to Mike to find some way to help. While his doctor would under no circumstance let him travel to Joplin to help with the recovery, he was able to provide support remotely and contribute to a devastated community looking to pick up the pieces.

He also was able to keep up with his personal life. While treatments meant



fourth in line to receive it. Before long, he was at the top of the list and had received his transplant. When he called his boss to tell her he had finally received a transplant and would be out of the office, she said his voice was already stronger and more animated than it had been before. Now, Mike is back at work and continues advocating for other patients through his involvement with DPC.

he did have to scale back on meeting friends for dinner or a movie, Mike could still travel to see his parents and attend the occasional concert.

Mike also found time to help advocate for other kidney patients. When he was at a dialysis clinic in Arizona, Mike heard about Dialysis Patient Citizens. Before long, he got involved and participated in a fly-in to Washington, D.C., where he met with policymakers on Capitol Hill and within the U.S. Department of Health and Human Services. He later became DPC's secretary and, eventually, treasurer.

He wasn't alone, however. Mike benefited from an immense support group at work. A number of his coworkers – some of whom were also suffering from chronic conditions of their own – were like on-

site nurses in the office. They helped keep him on track with his treatments.

Most importantly, though, they guaranteed he kept his head up no matter how difficult a day he was having. They had seen too many peers on disability who grew miserable over time, and their support network helped make sure everyone stayed positive.

This support continued through Mike's trying process of receiving a kidney transplant.

Like many other hopeful transplant recipients, Mike had a suitcase ready to go to the hospital as soon as he got the call that a kidney was ready. When that call came, he made the drive from Kansas City to St. Louis with his mother and called his family to push back their Christmas plans. But when he got to the hospital, he found out he would not be able to receive the transplant.

A short time after, another call came. A new kidney was ready, and Mike was the

So, after everything he's been through, what advice would Mike give to patients who suddenly find themselves on dialysis like he did?

"Don't give up and think that everything is over."

His primary piece of advice is to do exactly what he did: find something to not only keep yourself busy, but keep yourself positive. Search out a support network, inform yourself about the care options that are open to you, and take control of managing your care. If you do this, you will still be able to lead the life you want to on dialysis.

Like thousands of other dialysis patients, finding a way to do that took some time for Mike. Eventually, though, he found a routine that worked for him, allowed time to work a fulfilling job, and live life on his terms.

The same can be true for you, and the team at DPC is eager to help. If you want to speak with any of our advocates, or learn how to become one yourself, feel free to get in touch with us at www.dialysispatients.org or by calling (866) 877-4242. We can't wait to meet you!



Spring 2023 State Advocacy Update



By **Elizabeth Lively**, DPC Eastern Region Advocacy Director & **Pamela Zielske**, DPC Western Region Advocacy Director

Improving access to Medigap coverage is a top priority for DPC, and we are thrilled that legislation was introduced in multiple states this session to expand Medigap access to patients under the age of 65. Last month, DPC celebrated Governor Glenn Youngkin's (R) signing of Virginia bills SB 1409 and HB 1640 into law, guaranteeing access to affordable Medigap coverage for thousands of Virginians under 65 living with end-stage renal disease (ESRD).

The 2023 legislative session has been a busy and productive one for DPC's state advocacy efforts. Bills impacting dialysis patients have been introduced in multiple state legislatures and in most cases have moved quickly through the legislative process.

In Kentucky, Medigap legislation (HB 345) received unanimous approval from the House Health Services Committee on March 9, passed the House of Representatives 91-1 and also received



Anna Zelinske, ALS Society; Dean Large, Nebraska Patient Ambassador; Steve Kay, Nebraska Patient Ambassador; Nebraska State Senator Mike Jacobson; Hrant Jamgochian, CEO of Dialysis Patient Citizens; Wendy Schrag, Fresenius Medical Care; Jina Ragland, Nebraska AARP; Pamela Zielske, DPC Western Region Advocacy Director

unanimous approval from the Senate Health Services Committee on March 29 with a request for the bill to be placed on the Senate Consent Orders. This means the Senate votes a block of bills on the Consent Orders by a voice vote, guaranteeing passage. HB 345 was passed by the Senate on March 30 – the last day of the legislative session – and was signed by Governor Beshear on April 6.

Legislation to provide affordable access to Medigap coverage to the under 65 population was also introduced this session in Nebraska. The bill, LB 32, was heard in the Banking, Commerce, and Insurance Committee in February, and while it has not yet advanced to the General File, it is gaining growing support among constituents and local groups. DPC has continued to elevate the importance of Medigap in Nebraska through a robust media campaign.

Additional bills to expand Medigap have been introduced and are moving through the legislature in Hawaii, Minnesota, Indiana, Rhode Island, Vermont, and Texas.

A Medigap bill in Indiana (SB 312) was heard in the Senate Health and Provider Services Committee on February 15 with DPC providing testimony. The hearing testimony was received positively by committee members, but the chairman chose to hold the bill in committee and not move it to the Senate floor for consideration. DPC will continue working on passing a Medigap bill that provides affordable access to under-age 65 residents and expects to have a bill introduced again in 2024.

In addition to Medigap legislation, several states have introduced bills to enhance living donor protections and financial incentives, such as tax credits or reimbursement costs, which will help increase the number of kidneys available for transplant. Bills are moving through the legislature in Indiana, New Jersey, New Mexico, New York, North Carolina,

South Carolina, Vermont, and Virginia. Additionally, bills prohibiting discrimination in the organ transplant process were enacted in North Dakota and Virginia.

A number of bills have been introduced this session that align well with DPC's mission of expanding educational efforts for patients and their families, including several bills in Texas, as well as one in Virginia. In Texas, SB 1354 and HB 1876 both relate to the Rita Littlefield Chronic Kidney Disease Centralized Resource Center within the Health and Human Services Commission. This resource center would raise awareness about early detection of kidney disease, provide centralized information on access to clinical trials, promote greater health equity, and reduce the burden of kidney disease statewide. Additionally, the resource center would specifically provide information on CKD prevention and educational opportunities, including awareness campaigns, access to preventative screening, nutritional information, and professional resources for health care providers who treat patients with CKD and related illnesses.

DPC has also supported two additional bills in Texas, SB 1675 and HB 2983, which establish pilot programs to provide healthy, medical nutritional assistance to certain Medicaid recipients, including patients with kidney disease.

How can you help? We are always looking for DPC Patient Ambassadors to share their stories by writing letters to legislators, testifying at committee hearings, and participating in Action Alerts that are emailed to our members. Building strong relationships with legislators through the legislative process is how DPC is able to achieve success and improve the quality of life for its members and their families. To learn more about how you can help our state advocacy program, visit the DPC website (www.dialysispatients.org/get-involved/).



Kentucky State Representative Kimberly Moser and Elizabeth Livey, DPC Eastern Region Advocacy Director

The Making of An Advocate



By Gene Blankenship,
DPC Board of Directors

Thinking about Life

Sitting in my recliner watching the leaves

fall like big fat orange snowflakes, I see the trees begin to change colors. My immediate first thought is “How many more seasons of change will I see? Is this my last fall”?

Polycystic Kidney Disease (PKD) is a constant passenger in my life. Anytime you have a passenger with you for long periods of time, you will go through events together that stamp your life. For example, as a child, I watched Eugene Taylor Jr., my dad, hook himself up every day to his peritoneal dialysis port in his stomach. PKD also introduced me to death when my dad passed away just a few days after his transplant at St. Anthony’s Hospital in OKC. He was 33 and I was 12. Up to

that point in my life, I had never dealt with death. I don’t know if we patients like to admit how much we think of our mortality. I understand that thought process all too well though.

Coping with My Diagnosis

In 2003, I was diagnosed with PKD and told that I needed to take steps to preserve my kidney functionality. My doctor put me on blood pressure medication, which I was thankful for because the constant “migraine” type headaches I would sometimes encounter nearly disappeared. Later down the road, more medications would be prescribed, but that is something that appears to happen to us all that suffer from End-Stage Kidney Disease (ESRD). What I found out through a simple process of elimination was what my body would allow me to eat and what I had to do in order to maintain my three-kilo fluid limit. The most difficult part for me was eliminating whole milk and Coca-Cola floats. Once I became settled with the idea that dialysis is a must until a transplant comes along, I hit the cruise control button and moved forward with my life. For a long period of time, I just allowed the illness of PKD to simply take up real estate in my mind. After talking with many others who



suffer from ESRD, it appears that one of the monumental challenges for us all is overcoming those thoughts in our mind. It's tough, and the only way I found to conquer those was through prayer and helping others. My faith in Jesus is something that has, without a doubt, carried me through all my challenging times. If I am focusing my energy on improving a situation for others, I do not have the time to dedicate to the false worries that we all want to avoid.

Support

I am beyond blessed with my support system. My wife Stacy is my number one cheerleader - she is really amazing. I will never forget the night we received my first transplant call. We dropped the kids off at my In-laws and drove the three hours to Little Rock, Arkansas. We arrived, got checked in, and were on the way to the room to get prepped for surgery when my phone rang. It was my Transplant Social Worker telling me something was wrong with the kidney, which meant I would not get the transplant that night. Talk about devastation, going from the highest of highs to not so excited. Stacy is my rock though, and because of her consistent positive attitude, we don't dwell long. We mourn a few hours then it's on to the next one. Being listed at three separate facilities in two different regions, I feel like I have increased my chances as much as possible within reason.

Transplant Questions

After just three years of dialysis and the hope of a transplant living at the forefront of my mind, I began to ask questions. For example, the current CDC life expectancy is 77 years of age. The average number of people currently waiting for a kidney transplant is 100,000.



Should we look at organ donation education?

Should we re-evaluate our standards for donation?

Although a transplant is not a cure, many people treat it as one.

Should we look at what costs are covered for transplant medications and the lifelong screenings involved for transplant patients? I think transplant costs should be covered.

Some people will never be listed on the transplant list. Some will be listed and be in decent shape, but after long periods of time on dialysis, they will begin to develop issues. Before, their kidneys were cleaning and filtering waste and excess fluid from their blood 24 hours a day, 365 per year, but now dialysis machines are doing that just 16 hours per week. Let that sink in.

Advocacy

I know that I need to keep moving forward as a positive example for my kids. As a matter of fact, I would never tell my children to be quitters. I want them to run the good race and fight the good fight. I too, am doing this, as an advocate for both myself and other kidney patients. As you can tell from my transplant questions above, I was moving towards being a kidney patient advocate. At first, I began advocating alone, calling, writing, and emailing the different players in the community. Then after a few months, I became involved with a couple of different kidney/dialysis advocacy organizations. That to me was a new starting point. For example, I am now a Patient Ambassador and am on the Board of Directors for Dialysis Patient Citizens (DPC). I am thankful for organizations who fight for the benefit of the patients. Please join me in moving forward for all kidney patients; our lives may depend upon it!



Four Things You Should Know About the New Medicare Dental Rule



Andrea Moore, LMSW, Health Equity Specialist, Quality Insights Renal Network 5

1. Before January 1, 2023, Medicare would pay for a dental exam

only for patients who were actively seeking a kidney transplant. **Now**, the new Medicare dental rule will pay for a dental exam and dental treatment (e.g., dental filling, teeth removal, replacement of teeth, etc.) for patients actively seeking any organ transplant. If you are living with kidney disease—with or without dialysis—Medicare will not pay for preventative care, like teeth cleanings.

What this means for you: If you have Medicare and are actively seeking transplant, meaning you are undergoing transplant workup or are

actively on the transplant waitlist, you have more dental coverage now than you did before January 1, 2023.

2. Only 3 to 4 percent (%) of practicing dentists are enrolled as a Medicare provider, meaning these providers accept Medicare as payment for dental services.

Medicare will pay for dental exams and treatments only done by dentists, including oral surgeons, who are enrolled in Medicare.

What this means for you: If your current dentist is not enrolled in Medicare, your Medicare insurance will not pay for services performed by your dentist. When scheduling an appointment with a dentist always ask if they accept Medicare Part A or Part B for payment.

• If your dentist would like to enroll in

Medicare as a provider or supplier: Forms are available [HERE](#) and [HERE](#)

• If your dentist has questions about enrolling in Medicare and would like to talk with a Medicare Fee-for-Service Provider Enrollment contractor in your state: Contact list available [HERE](#)

3. As of February 2023, 40 states (including DC) have adopted Medicaid expansion. Medicaid expansion offers Medicaid-eligible adults dental benefits. The benefits Medicaid-eligible adults receive differ based on the state in which they live. Although most states have adopted the Medicaid expansion, only 39 percent (%) of dentists throughout the United States accept Medicaid as payment for dental services.

What this means for you: Not all

dentists accept Medicaid. However, if you have state Medicaid you will have an easier time finding a dentist who will treat you than if you have Medicare as your only insurance. When scheduling an appointment with a dentist always ask if they accept your state's Medicaid as payment.

What this means for you: Have your doctor or transplant team send a referral to the dentist before receiving dental treatment. The communication between the doctor and dentist is one of the most important steps to having your dental services paid for by Medicare.



Location	Status of Medicaid Expansion Decision
United States	Adopted-40 state (incl. DC); Not Adopted-11 states
Alabama	Not Adopted
Alaska	Adopted
Arizona	Adopted
California	Adopted
Colorado	Adopted
Connecticut	Adopted
Delaware	Adopted
District of Columbia	Adopted
Florida	Not Adopted
Georgia	Not Adopted
Hawaii	Adopted
Idaho	Adopted
Illinois	Adopted
Indiana	Adopted
Iowa	Adopted
Kansas	Not Adopted
Kentucky	Adopted
Louisiana	Adopted
Maine	Adopted
Maryland	Adopted
Massachusetts	Adopted
Michigan	Adopted
Minnesota	Adopted
Mississippi	Not Adopted

Location	Status of Medicaid Expansion Decision
United States	Adopted-40 state (incl. DC); Not Adopted-11 states
Missouri	Adopted
Montana	Adopted
Nebraska	Adopted
Nevada	Adopted
New Hampshire	Adopted
New Jersey	Adopted
New Mexico	Adopted
New York	Adopted
North Carolina	Not Adopted
North Dakota	Adopted
Ohio	Adopted
Oklahoma	Adopted
Oregon	Adopted
Pennsylvania	Adopted
Rhode Island	Adopted
South Carolina	Not Adopted
South Dakota	Adopted
Tennessee	Not Adopted
Texas	Not Adopted
Utah	Adopted

Location	Status of Medicaid Expansion Decision
United States	Adopted-40 state (incl. DC); Not Adopted-11 states
Vermont	Adopted
Virginia	Adopted
Washington	Adopted
West Virginia	Adopted
Wisconsin	Not Adopted
Wyoming	Not Adopted

- If you are seeking dental services as a person with Medicare insurance who is actively seeking transplant, it is important that your primary care doctor or transplant team speak with your dentist **before** you receive dental services. Communication between the dentist and your primary care doctor or transplant team is important to making sure your dental care will be paid for.

What this means for you: Have your doctor or transplant team send a referral to the dentist before receiving dental treatment. The communication between the doctor and dentist is one of the most important steps to having your dental services paid for by Medicare.

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Andrew Carr Knows There's More for Him

Kidney disease has been part of Andrew's life since he was 7 years old, when he was diagnosed with Hydronephrosis. Now 29, Andrew has had kidney disease for the majority of his life, but he's guided by the principle that his kidney disease doesn't control his life, he does.

Andrew began dialysis treatments when he was 19. While Andrew's exposure to kidney disease happened so early in his life, he does not remember how he felt about it at its outset, but vividly remembers the beginning of his dialysis treatments.

For three-and-a-half years Andrew persevered through his dialysis treatments, becoming deeply engaged in reading and writing to overcome the effects of his treatments.

Andrew was finally able to receive a kidney transplant after three-and-a-half years, which allowed him to get off of dialysis and attend college, the way he always wanted. He began studying social work, pursuing a career to help others suffering from medical disabilities.

While Andrew's life was finally back in his control, his kidney transplant failed after just a few years, and now has been back on dialysis for the last 5 years. He still loves reading and challenging his mind, and is currently writing a fiction novel on a hero's journey which he plans to publish. Andrew has never allowed dialysis to stop him from working to achieve his dreams.

Managing new careers while juggling dialysis treatments can be a challenge,

but Andrew has stayed active, engaged, and shown courage in seeking support from his employers while balancing his day job and treatment routine. At the beginning of his treatments, he recognized the need to take time and process what's happening to his body, and it was then that he realized what his body is capable of and how to adjust his lifestyle.

Andrew has since learned that it's important to continue trying new things and pursuing his goals, but it's okay if your body won't allow you to do all of the things your mind wants you to right away.

Andrew's perspective of taking his treatments seriously and listening to his body has guided his recovery, but



hasn't stopped his long-term goals and ambitions. His unique perspective of kidney disease and dialysis has made him passionate about deploying his knowledge and insights to help others.

Andrew hopes to attend the Dialysis Patient Citizens National Advocacy Day in Washington, D.C. this fall, bringing his powerful firsthand experience to lawmakers on Capitol Hill where he will continue raising awareness and advocating for others in the kidney disease community.

His long-term goal is to continue advocating for the dialysis and disabled communities at large before members of Congress, helping lawmakers understand the impact their policies have on the people they affect. Specifically, he aims to secure more resources for the disabled community so they will have the capacity to pursue their passions and live on their own terms.

Not yet 30, life with kidney disease is routine for Andrew, and he is eager to make his mark and explore all that life has to offer outside of dialysis. It's this determination to make a difference that propels Andrew's discipline and commitment to his dialysis treatments. Dialysis can take a toll, but Andrew is confident in his motivations and desires to live a fulfilling life, and to help other patients do the same.

Here's Andrew's advice to the dialysis community:

"It's important to take some time to breathe. Just trying to soldier on is not doing yourself credit, but know that you can overcome it. Nothing that I've tried to do in earnest has been unattainable". Andrew knows that there's more to do, more to see, and more to accomplish than what he's experienced so far, and

he will continue spreading this sense of purpose to the dialysis community as he pursues a career in advocacy.

Patient advocacy could be right for you too, and the team at DPC is eager to help. If you would like to speak with any of our advocates, or learn how to become one yourself, feel free to get in touch with us at www.dialysispatients.org or by calling (866) 877-4242. We can't wait to meet you!





Fighting Back Against Implicit Bias in Health Care

Tips for how to speak up and speak out against discrimination in a medical setting



Kirsten Weir

The receptionist requests two forms of identification from you, yet the White person in front of you required no identification to be verified.

A doctor who doesn't listen to you: Having just told the doctor you have knee problems, he recommended that you walk 30 minutes every day.

Are they just having a bad day – or is it implicit bias?

Implicit bias is an attitude or belief based on stereotypes about a particular group. People aren't aware of those biases; they happen automatically and unconsciously.

Yet they affect a person's decisions and behaviors. These biases can also affect interactions between people in medical settings, including hospitals or dialysis centers.

Implicit bias often comes out in the form of microaggressions, said Olufunke Awosogba, PhD, a psychologist at the University of Texas Southwestern Medical Center. "These aren't clear and obvious forms of



discrimination, but rather subtle jabs,” she said.

Encountering a steady stream of those jabs can take a toll. When people encounter implicit bias, they often have to stop and think: Did that person mean their statement to come off the way it sounded? Were they actually being rude, or am I overreacting? “It’s a mental burden for people to assess these not-so-obvious situations. In fact, it can actually be more of a burden than experiencing outright bias,” Awosogba said.

Besides causing stress and distress, implicit bias can lead to worse health outcomes. But by learning to recognize and address this sneaky form of discrimination, you can advocate for yourself and the loved ones in your care.

Implicit bias harms health

Unfortunately, everyone has implicit biases. Many different groups can be subject to implicit bias, including racial or ethnic groups, older adults, people with substance use disorders or mental health problems, people with obesity, members of the LGBTQ community, people with low incomes or little formal education, and those with disabilities.

Implicit bias affects how people are treated in medical settings. Research has found, for instance, that White health care professionals often exhibit implicit bias against Black, Hispanic, and other patients of color. Other studies show that bias against people who are overweight or obese can lead to medical discrimination.

Implicit bias can directly affect medical care. One study, for example, found White medical students believed Black patients felt less pain, and therefore needed lower levels of pain medications, compared to White patients—a false belief that could lead to more discomfort for Black patients. Research also shows that implicit bias among medical providers leads to poorer communication, less empathy, and differences in the treatments they recommend.

Doctors who score high on tests to evaluate their implicit bias are more likely to dominate conversations and spend less time with patients. As a result, their patients trust them less and have more trouble remembering what the doctor

told them. That could lead to confusion about their care and what they need to do to stay healthy. What’s more, people who are exposed to repeated discrimination might put off seeing their providers — or avoid seeking health care altogether, which can be particularly problematic for patients with kidney disease or kidney failure.

How to navigate discrimination

It can be hard to stand up to discrimination. Yet there are good reasons to push back against bias. Here are some tools you can use to make sure you’re respected as a person and a patient.

1. **Think it through:** Before meeting with your health care team, take time to think about what you’d like to happen. For instance, do you like to know all the background details of your condition? Or do you just want to know the next steps? Would it be helpful to record the conversation so you can listen to your doctor’s directions again at home? Or would

you like a printed summary to read over later?

2. **Set the tone:** Once you know what you want from your health care team, be proactive about asking for it. This can be especially helpful when meeting a doctor for the first time. “Let your provider know what kind of patient you are, and what you need for a successful relationship,” Awosogba said.
3. **Address concerns:** If you feel your health care team isn’t supporting you, your health can suffer. It’s important to speak up. “You might start your next visit by saying, “It’s important to me that I have a good relationship with those taking care of me. Is there something you need from me that will help you to help me?” Awosogba suggested.
4. **Make requests:** People with chronic kidney disease often see many different nurses or medical assistants for tests and treatments. It can be tiring to start from scratch each time. If there’s a provider you



feel comfortable with, ask if you can arrange to see them regularly. It might not always be possible, but it's worth a try.

5. **Pick your battles:** Dealing with microaggressions over and over can be exhausting. Sometimes, you might decide it's not worth the effort to push back or call someone out. If you don't have the bandwidth to deal with a given situation on a given day, don't feel guilty about putting it behind you. But if an interaction keeps weighing on your mind, consider what you need to move on. Would it help to discuss it with your provider, or with a loved one? Can you see a different doctor in the practice?
6. **Seek support:** One of the trickiest parts about microaggressions is that

it's not always obvious. Talking with friends and family members can help you make sense of a troubling interaction. And speaking with others who have dealt with similar experiences might help you feel better.

Above all, it's important for patients and caregivers to trust their experiences. "If we make it the norm to speak up, patients will become more empowered and the culture of our healthcare system will improve," Awosogba said. "You're the driver of your care, and it's important that your voice be heard."

This article was developed jointly by the American Psychological Association (APA) and Dialysis Patient Citizens Education Center as part of a partnership to educate dialysis patients and their families on the psychological and emotional aspects of managing kidney disease.

Check Your Bias at the Door: Tips for Health-care Providers

Implicit biases are universal, but there are steps you can take to keep them in check:

1. Get to know people as individuals. Ask questions and find ways to connect. When you realize what you have in common, you're less likely to lump people into a group that's "other" than you.
2. When you start to think in terms of stereotypes, stop yourself and think of a counter example. If you find yourself assuming an older adult is forgetful, for example, think of an older adult you know who has excellent memory and thinking skills.
3. Put yourself in your patient's shoes. Are they dealing with stressful life situations that could be getting in the way of following the treatment recommendation? Consider their circumstances, not their identity.

Plan ahead. Think about when you're most likely influenced by implicit bias. When you're rushing to get things done? When patients look different from you? Then make a plan for those situations. For example: When I meet with a patient of a different race, I'll ask a question about their interests before discussing medical details.

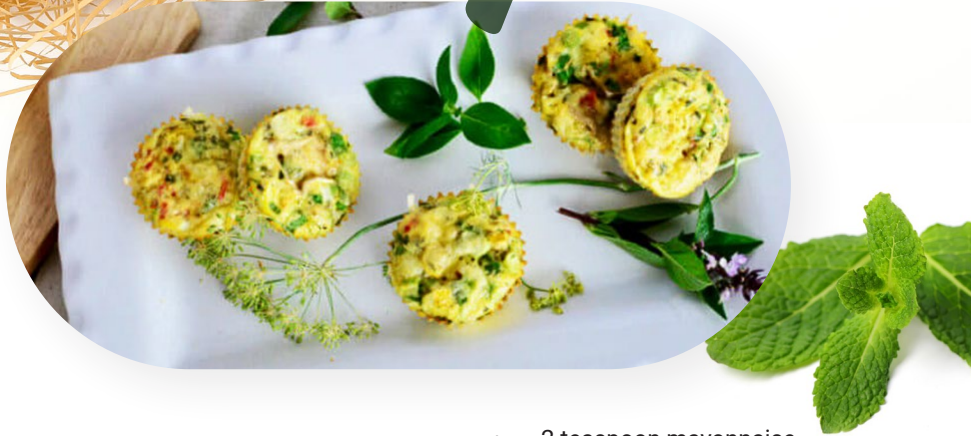
Health care is a team sport. If you take time to engage with your patients, you'll be more successful in working together to improve their health and wellbeing. That's a win-win for providers and patients.

For more information, visit the implicit bias resources website created by the [American Psychological Association](#).



Kidney-Friendly

Recipes



Thanks to Jessianna Saville, MS, RDN, CSR, LD, CLT, a member of the Ed Center Advisory Council and Founder & CEO of the Kidney Nutrition Institute, for providing us with two

great kidney-friendly recipes* to kick off summer!

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

Summer Harvest Egg Muffin Cups

Recipe developed by Jessianna Saville, RDN, Renal Nutrition Specialist

Ingredients

Makes 12 Servings

- 1 cup vegetables diced small or shredded (we did 1/3 c carrot, 1/3 c yellow squash, 1/3 c red pepper)
- 1 teaspoon oil
- 8 eggs
- 1 tablespoon fresh herbs (we used dill, basil, and parsley)
- 3 stalks green onion green and white thinly sliced

- 2 teaspoon mayonnaise
- Brie optional, small slices
- 1 teaspoon lemon zest to taste

Instructions

1. Sauté vegetables in oil until barely softened. Set-aside to cool. Whisk eggs and mayo together in bowl. Add herbs and sliced green onions. Add cooked vegetables. Pour into 12 individual muffin tins. Top with small slice of brie (opt) Silicon muffin tins are best because the muffins can easily pop out of those. Alternatively, you could make this in an 9x9 dish like a breakfast casserole.
2. Bake at 350 for about 20-25 minutes until middle of each muffin is set. Add sprinkle of lemon zest to top of each muffin.

Notes

These store really well in freezer and can be made ahead. If making ahead add the lemon zest to the egg batter before cooking.*Alternative toppings include feta and very sharp thinly grated cheddar cheese (1/4 tsp per muffin)* To lower the phosphorus content further, replace 4 eggs with 6 egg whites. With egg white replacement fat content is 3.5 gm and phos is 46 mg.

Chilled Cucumber Low Potassium Soup

Recipe developed by Clarissa Paimanta, RD and tested by Lydia Safadi, MA, RD, LDN.

Ingredients

Makes 3 servings

- 1 large cucumber, about 2 cups, deseeded and chopped
- ½ avocado chopped
- 1 spring onion, both green and white parts, roughly chopped
- ½ cup plain coconut milk yogurt
- 2 tablespoon olive oil
- 2 tablespoon low sodium homemade pesto
- 4-5 fresh mint leaves
- ½ clove garlic
- ¼ - ½ jalapeno, seeds removed then minced, to taste
- ½ lemon juiced
- 1 dash of salt to taste
- 1 dash of black pepper to taste

Instructions

In a powerful blender, add all ingredients. Blend until smooth, adding water as needed to achieve desired consistency. Adjust seasoning to taste. Place in the fridge to chill for at least 4 hours. Serve chilled with a drizzle of olive oil, cucumber slices, and/or a dollop of coconut yogurt as garnish.

Tip

Avocado is high in potassium, but that does not mean you have to avoid it. Our strategy is to include a small portion, then balance it out with low potassium components, like cucumbers. This creates an overall dish that is reasonable in potassium.



Dialysis Cruising



By Joanne Smith, RN,
Kidney Care Advocate,
Fresenius Kidney Care

Whether you are on
in-center hemodialysis,
peritoneal dialysis, or
home hemodialysis

taking a cruise is an option for you. It takes
a bit of planning, but what vacation doesn't?

I have experienced several cruises
that have offered services for dialysis
patients. The treatments were performed
in staterooms on the lower level of the
ship, close to the infirmary.

We used a portable reverse osmosis
machine attached to the water from the
bathroom to provide the purified water
needed for the dialysis treatments.

We used jugged acid and bicarbonate
solutions and a standard dialysis
machine.

Your current doctor's orders are followed
for your estimated dry weight, dialysis
bath, needle size, and treatment time.

The staff are well groomed in the
machines and water systems and are
required to have at least three years
of experience in performing in-center
dialysis.

Typically, the patient to staff ratio
was two patients for every nurse or
patient care technician. In addition, a
nephrologist is assigned to round on
each patient that is having in-center
dialysis administered. If you are a home
peritoneal dialysis patient or a home
hemodialysis patient, you will not need



to be seen by a nephrologist or nurse.
Home patients typically will have their
supplies delivered to the port to be
loaded onboard and sent to their rooms.

You should always consult with your
current health care team before deciding
if you are stable enough to travel.

The company that you plan your cruise
with will require medical information
including, but not limited to, a current
EKG, a current history and physical, most
recent lab results, current medication
list, three flow sheets, and a lab result
for a Hbsag (hepatitis status) within six
months of your sailing date.

It is recommended that you hand carry
your last three treatment sheets, a
copy of your latest lab results, and all

medications you will need while away.

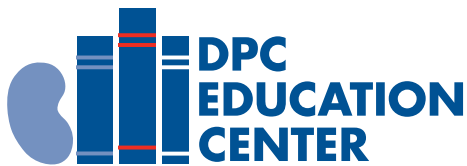
Unfortunately, Medicare and Medicaid
have never covered dialysis cruise
treatment costs, but some supplemental
insurance companies will reimburse a
percentage of the cost. I suggest you
contact your insurance company to see
if they will cover any of the cost before
making your plans. You will have to deal
with your insurance company as the
dialysis cruise companies will not do that.

Your cruise coordinator will inform you
of all requirements needed to travel.

With proper planning, there is no reason
why being on dialysis should hold you
back from traveling.

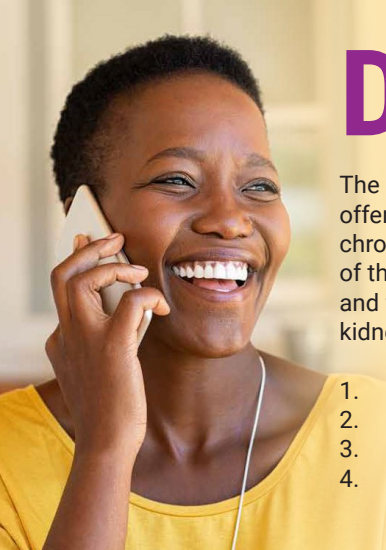
Happy travels, stay safe!!





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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 3:00 pm Eastern for one hour.



Join the call: Dial: 866-230-9002

Enter Meeting Code: 420 835 078#

Learn more and RSVP at www.dpcedcenter.org



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