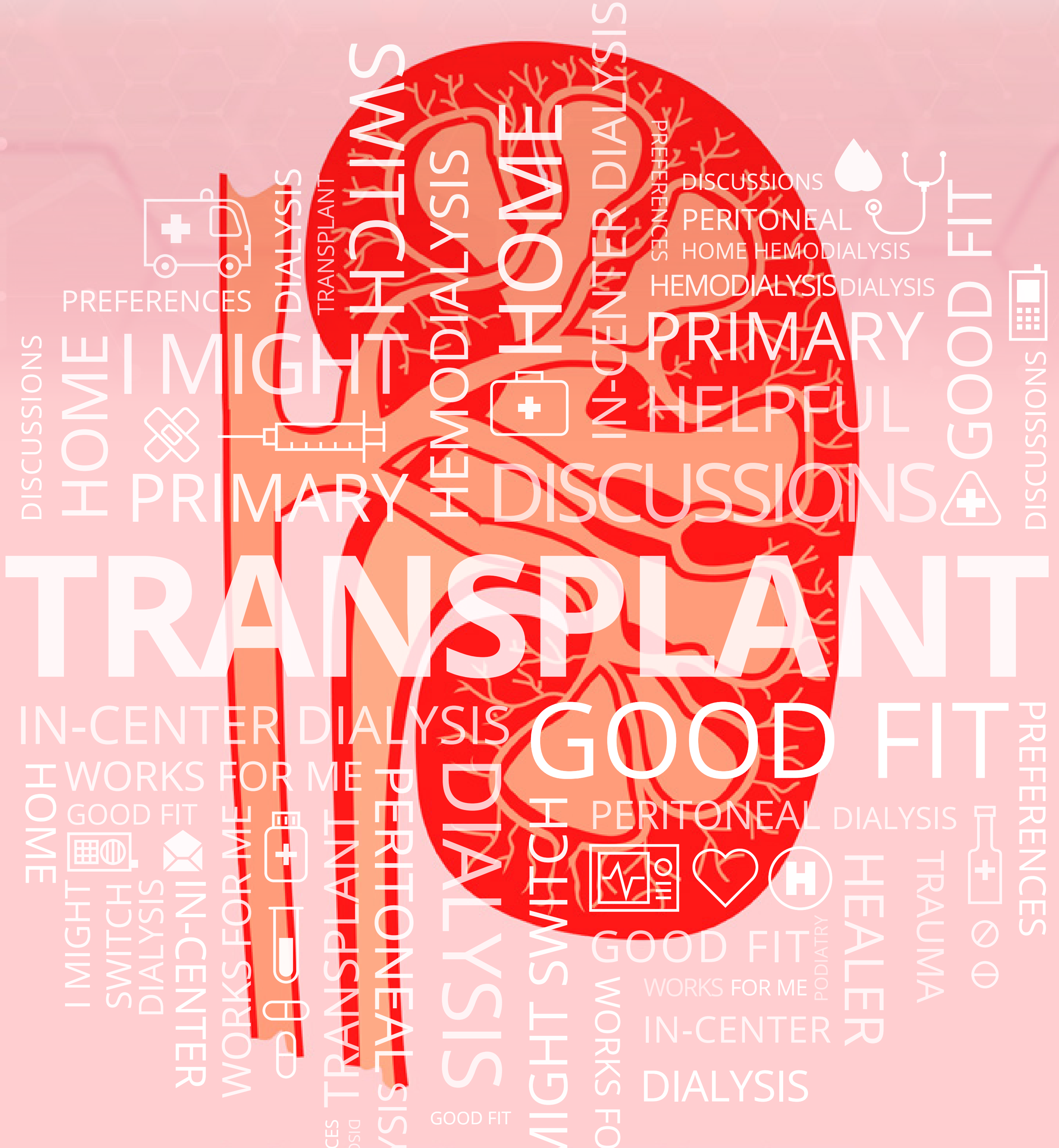
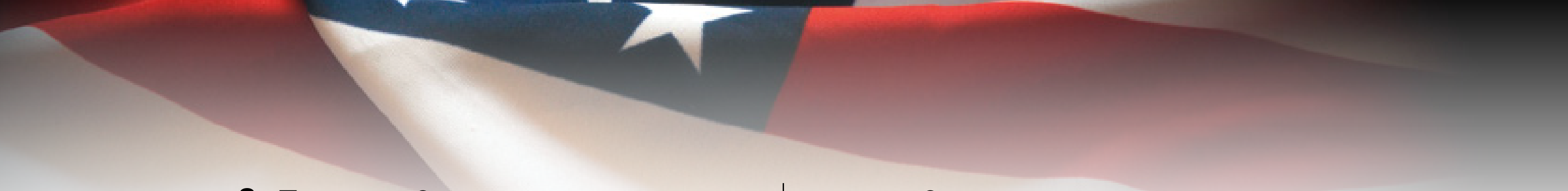
issue number 22

The Citizen Kidney

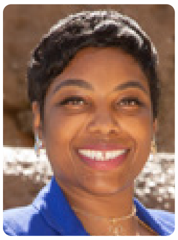
DPC EDUCATION CENTER

A publication of Dialysis Patient Citizens (DPC) Education Center





President's Message



Welcome to this issue of The Kidney Citizen. The theme of treatment options is particularly meaningful to me because my own path through kidney disease taught me a powerful lesson: the choices we make matter, and having the right information makes all the difference.
When I started dialysis, I chose in-center treatment. I know many patients are encouraged to explore home modalities, and those options work wonderfully for many people. But for me, in-center dialysis was the right fit. I valued the clinical support and the structure it provided. This was my first important lesson – there's no one-size-fits-all approach to kidney care.

As I continued on dialysis, I began preparing for transplant. That's when I discovered something that changed my strategy entirely: New York, where I live, has some of the longest transplant wait times in the country. Armed with this knowledge, I took action. I got listed at multiple transplant centers, including in Pennsylvania, and it was at the University of Pennsylvania where I ultimately received my kidney.

More than a decade later, I'm still thriving with the kidney I received. But here's what I want patients to understand: both choices are valid. Some patients are right to accept the first available organ. Others, like me, benefit from waiting. The key is making an informed decision based on your individual situation.

As many of you know all-too-well, the transplant process is long – it can take months of testing, evaluations, and patience. But persistence pays off. And for those who may not be transplant candidates, please know that dialysis continues to evolve. Home dialysis options are improving. New therapies like hemodiafiltration are emerging. Researchers are working on revolutionary approaches like xenotransplantation and blood type-neutral organs that could transform who can receive a kidney.

Innovation doesn't stand still. Even if you researched your options years ago, treatments available today might be completely different. In this issue, you'll find stories from patients who navigated different treatment paths, along with insights from healthcare professionals about cutting-edge therapies.

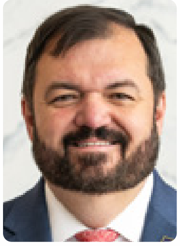
My message is simple: stay curious, stay informed, and never stop advocating for yourself. The more you know about what's available, the better equipped you are to shape your own care and your own future.

Sincerely,

Merida Bourjolly

Merida Bourjolly,
President of DPC Education Center Board of Directors

CEO's Message



Thank you for reading this issue of the DPC Education Center's magazine, The Kidney Citizen. As we focus on treatment options available to kidney disease patients, I want to share my own journey – one that has shown me firsthand how much the landscape of kidney care has evolved. I was diagnosed with kidney disease 14 years ago, shortly after joining DPC. At the time, doctors determined through a process of elimination that I had IgA nephropathy, but there was no treatment available. For a decade, I lived with that diagnosis, doing what I could to manage my condition.

Ten (10) years later, everything changed. My nephrologist told me there were now multiple treatment options available and suggested we confirm my diagnosis with a biopsy. This was a surgical procedure where they removed part of my kidney for testing. The recovery was difficult – I was in pain for well over a week. But the results were surprising: I didn't have IgA nephropathy after all. I had FSGS. Three years ago, at Kidney Week hosted by the American Society of Nephrology, I met representatives from Natera, a genetic testing company. They explained that they could test for over 200 different variations of kidney disease. Since my biopsy showed FSGS, and there are six different strains of it, they suggested genetic testing. The remarkable thing? All it required was a simple swab – no surgery, no pain, no recovery time. When my nephrologist ordered the test, we discovered something unexpected: I actually had Alport syndrome, and the FSGS was secondary to it. This diagnosis matters because today, there are specific therapies available for different types of kidney disease, many of which have gone generic and are now affordable.

This brings me to an important message for all of you. Research shows that more than one in five patients develop kidney disease because of a genetic condition. Many kidney disease patients aren't the only ones in their family facing this challenge. Even if you are currently on dialysis or have received a transplant, I encourage you to talk to your loved ones about their kidney health. Let them know about genetic testing – a simple swab that can identify exactly what type of kidney disease they may have. There are now therapies that can slow kidney disease progression and potentially help someone avoid kidney failure entirely. Early detection and proper diagnosis can make all the difference.

DPC'S Education Center exists because so many people with ESRD – including some of our board members – crashed into dialysis without warning, wishing they had known earlier. While DPC focuses on dialysis patient advocacy, the Education Center works to go upstream – to educate others about kidney disease and increase awareness. We want to help people avoid what so many of our members experienced. I'm grateful we're focusing on treatment options in this issue.

Sincerely,

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

Finding My Path

THROUGH TREATMENT OPTIONS

By Cheri Rodriguez Jones
DPC Board Member

I was seven years old when doctors diagnosed me with a rare kidney disease. The 1980s and 90s didn't offer much in terms of treatment – just managing symptoms and preserving kidney function as long as possible. Hospital visits became routine. At 19, after some tests, my doctor called with surprising news: "You need to start dialysis." While unexpected, I'd always known dialysis was coming eventually. By then I was already a mother to my infant son.

Discovering What Worked for Me

The medical team recommended peritoneal dialysis so I could do treatments at home. I trusted their guidance. It worked well for about seven months until I developed peritonitis – an infection that kept returning. Eventually, the infection became severe enough that I had to switch to in-center hemodialysis.

Something unexpected happened. I lost 30 pounds of fluid and went off all blood pressure medications. I hadn't realized the peritoneal dialysis wasn't working as effectively for my body. When they said I could return to PD, I asked to stay on in-center hemodialysis instead. It simply worked better for me.

New Possibilities Through Connection

After my first transplant eventually failed and I returned to dialysis, everything had changed. Home hemodialysis had become an option, and social media had opened up whole new communities. Before Facebook groups, you could only learn from people at your dialysis center.

In an online group, I read about patients doing overnight home hemodialysis while they slept. I was working with a long commute, and this could transform my life. I asked my center about it.

"We don't have a program for that."
"What do I need to do to make it happen?"

I started writing letters. Three years later, after they established protocols, I got my overnight home hemodialysis program.

Moving Forward

Living with end-stage renal disease is overwhelming. Which treatment should I choose? Am I making the right decision?

Here's what I want you to know: there's hope, even when it doesn't feel that way. Many people have been exactly where you are, and that means countless people who understand and can share their experiences.

Don't be afraid to ask questions. Seek out others who've walked this path. And when you need something – whether it's a different treatment option or a program your center doesn't yet offer – speak up. Write that letter. Yes, it can take time. But it works.

I started dialysis young, before I'd ever taken a real vacation, and I finally got to take my first one just two years ago. Last year, I finally visited family in the Netherlands – something I'd dreamed about my entire life.

My philosophy now: do the things you want to do. Even if the timing isn't perfect, if you're able, just do it anyway. We all know tomorrow isn't promised. Find your joy where you can.

Treatment options that work for one person may not suit another. What worked for me at one stage didn't work at another. But staying informed, connecting with others, and being willing to fight for what you need – those things make all the difference.

You're not alone in this.

Staying Hopeful Through the Wait

By Hasan Artharee,
DPC Board Member

Polycystic kidney disease (PKD) runs in my family. I watched my grandmother go through dialysis when I was young, and later my mother during my college years. So, when I was diagnosed with PKD at 22, I understood what the future might hold.

The diagnosis came after my blood pressure kept rising and I needed medication. My doctors checked my kidneys and found that PKD was affecting my blood pressure and other systems. They told me that based on my family history, I'd probably need dialysis or a transplant by my 40s. For the next 13 years, it was about monitoring – annual checkups, tracking my creatinine levels, watching how the disease progressed. Some people with PKD never need dialysis, even in their 60s and 70s. I hoped I might be one of them.

At 35, my kidney function declined enough that dialysis became necessary though. Before I even started treatment, I went through the workup at the hospital and got listed for transplant. I wanted to be ready.

Because I was working, coaching my kids, and living a busy life as a parent, I chose peritoneal dialysis. The flexibility appealed to me – I could do it at home or even at work if needed. I didn't want to spend so much time at a center. But peritoneal dialysis meant dealing with treatment every single day and adjusting to having a catheter in my stomach.

After about six months, I developed a hernia from the amount of fluid going in and out during treatment. While the hernia healed, I switched to hemodialysis. That's when I discovered something surprising: I actually preferred it. Hemodialysis was only three days a week. I got my weekends back. I could live a better life not having to do treatment every single day.

I stayed on hemodialysis for five and a half years before receiving my transplant. September 18th marked seven years with my kidney, and so far, everything is going well. Life improved dramatically after transplant. No more dialysis wearing down my body. Now my busiest task is taking my medications and making sure I don't forget anything – I don't want anything to happen to this kidney.

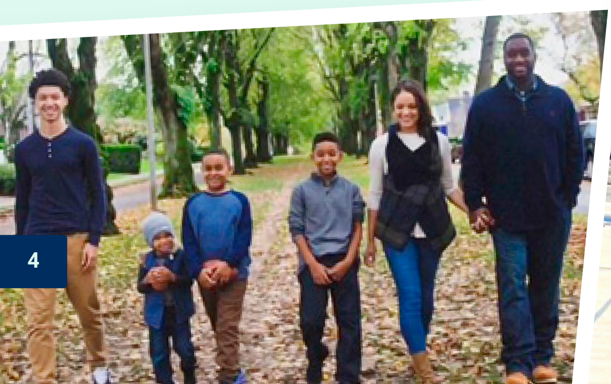
The hardest part wasn't the physical toll, though that was real. It was the mental aspect. After about four and a half years on dialysis, I started losing hope. Would this ever happen for me? I was tired of coming to treatments, tired of feeling worn down afterward. That hopelessness can really bring you down.

But staying positive became my goal. I communicated regularly with my doctors because even though the wait felt endless, talking and staying informed gave me hope. I was preparing for the day I'd get the call. The mental challenge was enormous – dealing with the disease while trying to live your regular life, adjusting to not working, navigating disability, Medicaid, and Medicare. At 35, it felt overwhelming to deal with all of this so young.

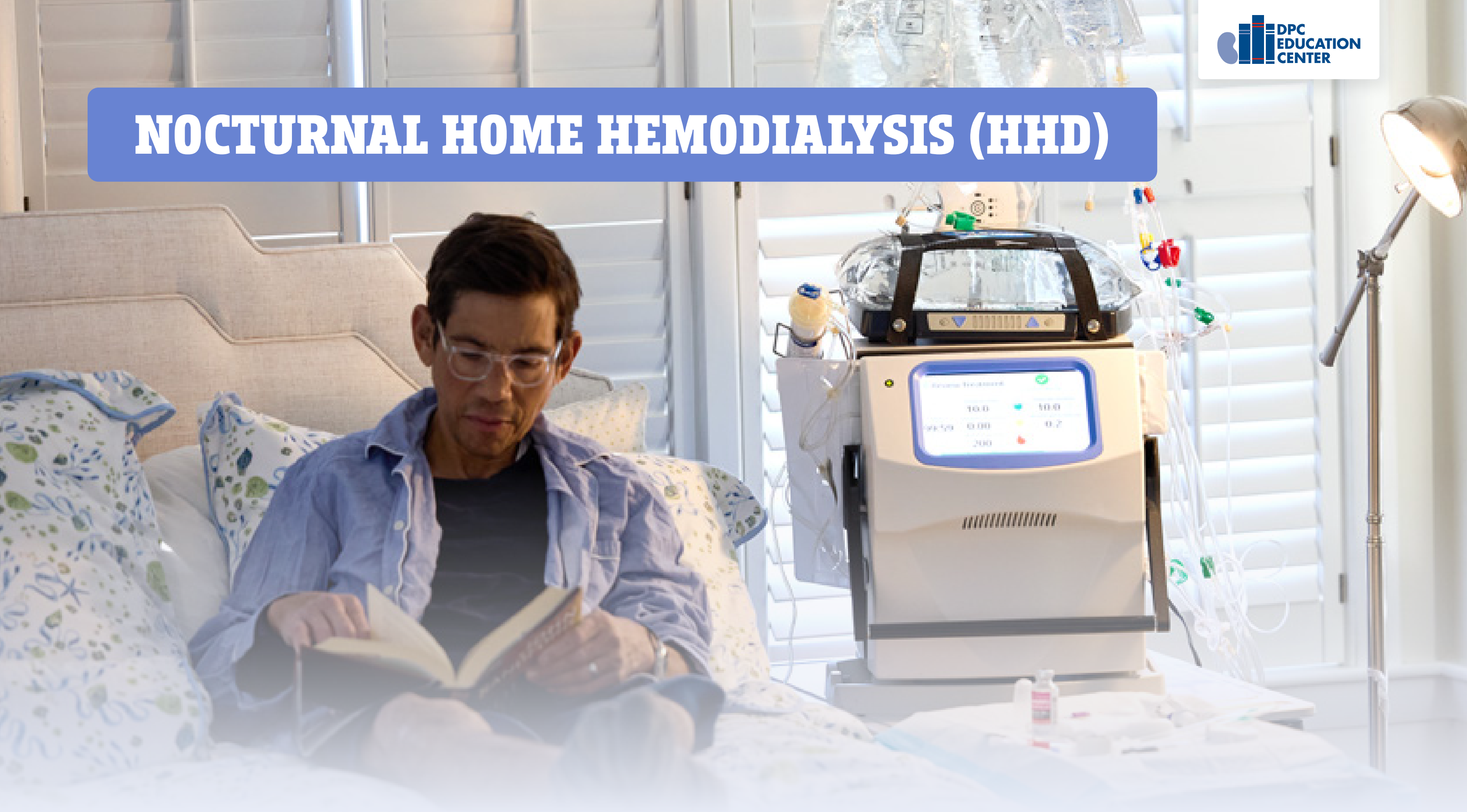
I tried to stay upbeat. Many people told me they didn't know I was on dialysis because I didn't look too different. I tried not to show it. I know that approach doesn't work for everyone, but it helped me keep moving forward – still trying to live as normal a life as possible.

My advice to anyone starting dialysis or waiting for a transplant is to not lose hope. After years of dialysis, it's easy to feel like it will never happen. But staying hopeful is key. Keep communicating with your doctors. Stay informed. Keep preparing for that day when you do get the call.

The wait is hard. The treatment is taxing. But holding onto hope and trying to maintain your life as much as possible – that's what gets you through until your moment comes.



NOCTURNAL HOME HEMODIALYSIS (HHD)



Kidney Replacement Therapy with Less Impact on Daily Life

By Brigitte Schiller, MD, FACP, FASN, SVP
Medical Officer:
Home Therapies,
Global Medical Office,
Medical Affairs, Fresenius
Medical Care

Important progress has been made in the delivery of dialysis. The “one size fits all” approach with standard thrice-weekly in-center hemodialysis shifts toward personalized care, emphasizing quality of life, independence, and symptom management tailored to each person’s clinical and personal needs. Kidney replacement therapy at home is a critical ingredient in this effort.

While kidney transplantation remains the gold standard of end-stage kidney disease (ESKD), most people require dialysis before receiving a transplant. As patients await transplantation, selecting the appropriate dialysis modality is critical.

Person-centered Kidney Replacement Therapy Choice

Person-centered care requires understanding each person’s clinical needs, personal values and beliefs, hopes for the future, and life circumstances.

Education about all available options of kidney replacement therapy, in-center and home dialysis, often results in patients preferring home dialysis modalities, which offer greater flexibility and independence.

Peritoneal dialysis, provided as continuous ambulatory PD (CAPD), or automated PD (APD), is often the initial choice at the start of dialysis need. People of all ages undergo peritoneal dialysis. In recent years, people older than 65 years are increasingly choosing PD as their modality choice, allowing them to participate in life’s activities (1).

Hemodialysis at home is delivered as more frequent home hemodialysis (HHD) with most people undergoing 4-6 treatments/week (2). Treatment length ranges between 2.5 to more than 6 hours based on individual clinical needs and lifestyle preferences. HHD has been successfully used since the 1960s and 1970s. It re-emerged in the US in the mid-2000s and has quadrupled over the past 20 years (3). Today, more than15,000 people in the US undergo more frequent HHD. Approximately 40% of people choose the therapy within the first year of dialysis, while most people transition later to HHD, with many of them after 5+ years of dialysis. As with PD, increasing number of older patients now choose HHD, reflecting the increased expertise in safely providing home dialysis to older people with other ailments (1).

Patients who choose home dialysis consistently highlight independence, flexibility and the pursuit of normality with time for work, family, friends, socializing and caring, travel and participation in daily life. Benefits of more frequent HHD include improved survival (4-6) reduced cardiovascular risks (7-9), better sleep quality (10), shortened post dialysis recovery time (11,12) and better overall quality of life (13).

Many patients report satisfaction with their decision to undergo home therapies as it provides them with greater control over their lives.

Nocturnal HHD

Nocturnal HHD, performed overnight while patients sleep, is an appealing option with limited impact on daytime burden with dialysis. The NxStage System One / VersiHD is approved by the FDA for HHD at night with care partner and for daytime dialysis with or without a care partner (solo HHD).

Evidence supporting Nocturnal HHD

Several observational studies conducted in Canada, the US, and internationally have shown survival advantage with nocturnal HHD (14-19). Patients undergoing nocturnal HD have survival comparable to people treated with a cadaver kidney transplant (6). A more recent study in the US confirmed these results in patients undergoing nocturnal HHD for 20 or more hours of therapy during at least 4 sessions per week (20). One contrasting study, the Frequent Hemodialysis Network (FHN) Nocturnal Trial reported worse outcomes in the nocturnal group compared to conventional HHD. However, these findings should be interpreted cautiously due to small sample size and unusually low death rates in the conventional group limiting generalizability of the data (21).

Considering the existing evidence, many nephrologists consider nocturnal hemodialysis with gradual removal of toxins and fluid over a longer treatment time a superior modality which is not often prescribed in the US (22).

Who might consider nocturnal HHD?

- Patients who could benefit from nocturnal HHD include those with cardiovascular health issues, large fluid gains, uncontrolled phosphorus levels, blood pressure drops during dialysis, long recovery times after dialysis.
- Patients who experience burn-out with daytime dialysis might consider taking the therapy out of their daytime and dialyzing while sleeping.
- Patients whose daytime activities and/or the availability of a care partner favor nighttime dialysis.
- Patients who switch from PD to another modality can continue home dialysis at night with this modality choice.
- Patients transitioning to nocturnal HHD often report notable improvements in energy and post-dialysis recovery.

Patient Voices: Real World Experiences

Personal Experiences show the potential life-changing benefits of nocturnal HHD: “We always talk about transplants being the gift of life, but quite frankly, nocturnal home hemodialysis has been my gift of life.”

One patient described their initial transition to nocturnal HHD:
“I started with five-hour treatments in my recliner during the evening, planning not to sleep. But to my surprise, I found I slept during most of the treatment and the needles were stable in place. My confidence grew after several treatments and soon I’ll move to overnight treatments in bed.”

Conclusion

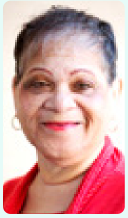
The positive experiences of many patients with nocturnal HHD motivate ongoing support and awareness of nocturnal HHD as an alternative modality to daytime HHD. Overnight dialysis, when less disruptive to daily routines, improves quality of life. Benefits of outcomes comparable to cadaver kidney transplantation come from observational studies. Safety protocols including securing needles appropriately and including blood detection devices at the needling sites, seek to reduce the risk of serious adverse events, which are very rare (22).

Although nocturnal dialysis still carries burdens, patients often find it less burdensome than other dialysis options. People undergoing dialysis and considering nocturnal HHD are advised to discuss the option with their nephrologist to ensure safe and individualized person-centered therapy.

References:

1. USRDS, ADR 2024, Figure 2.7
2. USRDS, ADR 2024, Figure 2.11a
3. USRDS, ADR, 2024, Figure 1.8
4. Weinhandl ED, Liu J, Gilbertson DT, Arneson TJ, Collins AJ. Survival in daily home hemodialysis and matched thrice weekly in-center hemodialysis patients. J Am Soc Nephrol 23: 895–904, 2012
5. U.S. Renal Data System, USRDS Annual Data Report, vol 2, Table 6.3.; 2015 & Matched NxStage patient data on file.
6. Pauly RP, Gill JS, Rose CL, Asad RA, Chery A, Pierratos A, et al. Survival among nocturnal home haemodialysis patients compared to kidney transplant recipients. Nephrol Dial Transplant. 2009;24(9):2915–2919
7. Culleton BF, Walsh M, Klarenbach SW, et al. Effect of Frequent Nocturnal Hemodialysis vs Conventional Hemodialysis on Left Ventricular Mass and Quality of Life: A Randomized Controlled Trial. JAMA. 2007;298(11):1291–1299.
8. FHN Trial Group; Chertow GM, Levin NW, Beck GJ, Depner TA, Eggers PW, Gassman JJ, Gorodetskaya I, Greene T, James S, Larive B, Lindsay RM, Mehta RL, Miller B, Ornt DB, Rajagopalan S, Rastogi A, Rocco MV, Schiller B, Sergeyeva O, Schulman G, Ting GO, Unruh ML, Star RA, Kliger AS. In-center hemodialysis six times per week versus three times per week. N Engl J Med. 2010 Dec 9;363(24):2287-300. Epub 2010 Nov 20. Erratum in: N Engl J Med. 2011 Jan 6;364(1):93.
9. Kotanko P, Garg AX, Depner T, Pierratos A, Chan CT, Levin NW, et al. Effects of frequent hemodialysis on blood pressure: Results from the randomized frequent hemodialysis network trials. Hemodial Int. 2015;19(3):386–401
10. Jaber BL, Schiller B, Burkart JM, Daoui R, Kraus MA, Lee Y, et al. Impact of Short Daily Hemodialysis on Restless Legs Symptoms and Sleep Disturbances. Clin J Am Soc Nephrol. 2011 May;6(5):1049–56.
11. Jaber BL, Lee Y, Collins AJ, Hull AR, Kraus MA, McCarthy J, et al. Effect of daily hemodialysis on depressive symptoms and postdialysis recovery time: Interim report from the FREEDOM (Following Rehabilitation, Economics and Everyday-Dialysis Outcome Measurements) Study. Am J Kidney Dis. 2010;56(3):531–539.
12. Lindsay RM, Heidenheim PA, Nesrallah G, Garg AX, Suri R. Minutes to recovery after a hemodialysis session: a simple health-related quality of life question that is reliable, valid, and sensitive to change. Clin J Am Soc Nephrol. 2006;1(5):952–959.
13. Bonenkamp AA, van Eck van der Sluijs A, Hoekstra T, Verhaar MC, van Ittersum FJ, Abrahams AC, et al. Health-Related Quality of Life in Home Dialysis Patients Compared to In-Center Hemodialysis Patients: A Systematic Review and Meta-analysis. Kidney Med. 2020;2(2):139–54. 2019;20(1):1–8.
14. Lacson E Jr, Wang W, Lester K, Ofsthun N, Lazarus JM, Hakim RM. Outcomes associated with nocturnal hemodialysis among patients in the US. J Am Soc Nephrol. 2012;23(4):687-695
15. Johansen KL, Zhang R, Huang Y et al. Survival and hospitalization among patients using nocturnal and short daily compared to conventional hemodialysis: a USRDS study. Kidney Int 2009;76(9):984-990.
16. Nesrallah GE, Lindsay RM, Cuerden MS et al. Intensive Hemodialysis Associates with Improved Survival Compared with Conventional Hemodialysis J Am Soc Nephrol 2012;23(4):696-705.
17. Mathew A, McLeggon JA, Mehta N et al. Mortality and hospitalization in intensive dialysis: a systemic review and meta-analysis. Can J Kidney Health Dis 2018; 5:1-18
18. Rivara MB, Adams SV, Kuttukrishnan S et al. Extended-hours hemodialysis is associated with lower mortality risk in patients with end-stage renal disease. Kidney Int 2016;90(6):1312-1320.
19. Nishio-Lucar AG, Bose S, Lyons G, Awuah KT, Ma JZ, Lockridge RS et al.: Intensive Home Hemodialysis survival comparable to deceased donor kidney transplantation. Kidney Rep Int 2020;(5):296-306.
20. Rocco MV, Lockridge RS Jr, Beck GL et al. The effects of frequent nocturnal home hemodialysis: The Frequent Hemodialysis Network Nocturnal Trial. Am J Kidney Dis 2015; 66(3):459-468.
21. Liu F, Abra G, Gupta N, Schiller B, Rivara M. How I treat Nocturnal HHD-An under-prescribed but essential home dialysis modality in the US Clin J Am Soc Nephrol, e-publication, Oct 2025.
22. Platnich JM, Pauly RP: Patient training and patient safety in home hemodialysis. Clin J Am Soc Nephrol 2024;19:1045-1050.

Treatment Options for End Stage Renal Disease



By Nancy Scott,
DPC Education Center
Project Manager

Many patients crash into dialysis and are placed into in-center dialysis centers. Hopefully, more providers are educating patients about treatment options. When patients are engaged and educated about their respective conditions, they tend to have a better quality of life both physically and mentally. The world of kidney disease is forever changing and making a significant impact on the journey of renal patients.

Explore Potential Treatment Options for Kidney Failure[1]

A kidney transplant is often the best possible treatment option for patients with kidney failure. If you aren't eligible for a kidney transplant, or if you are awaiting a kidney from a living or deceased donor, you will need dialysis.

When it comes to treating kidney failure with dialysis, you have certain options. From dialyzing at home to getting treated at a center, discover which one could better suit your lifestyle.

Home treatment options

Peritoneal Dialysis (PD)

Peritoneal Dialysis (PD) is a needle-free treatment done at home that uses the lining of the abdomen (or belly) to filter waste from the blood. It is the treatment most similar to your natural kidney function. Some of the potential benefits of PD include:

- Control of your own treatment and a more flexible schedule
- Greater ability to pursue personal interests
- Preservation of remaining kidney function, leading to enhanced clinical outcomes
- Better transplant outcomes because PD is also gentler on the body, including the heart.

Home hemodialysis (HHD)

HHD works just like in-center hemodialysis by using an external filter to clean toxins from your body, only the machine is smaller and more user-friendly. There are many potential benefits to HHD, such as:

- The ability to dialyze in the comfort of your own home
- Greater ability to travel
- Shorter recovery time after treatments
- Fewer medications required

Dialysis center options

In-center hemodialysis

In-center hemodialysis requires you to

visit a dialysis center three times per week. It uses a machine to filter your blood and clear toxins from your kidneys. In-center hemodialysis offers several potential benefits, which include:

- The chance to socialize with other patients and staff
- A personalized care team
- No supplies to store at home

In-center nocturnal dialysis

In-center nocturnal dialysis allows you to dialyze in-center overnight three times per week, for 6–8 hours while you sleep. It also includes potential benefits such as:

- No interference with daytime schedule
- An improved appetite
- Better blood pressure control

The Next Frontier of Transplant Medicine[2]

More than 31,000 lifesaving organ transplants have been performed since Mayo Clinic's first organ transplant in 1963. Through advances in organ preservation, stem cell therapies, regenerative medicine, bioengineering and artificial intelligence (AI), Mayo Clinic physicians and scientists have been able to improve patient outcomes throughout the transplant journey.

From restoring organs that would otherwise not be safe for transplantation to advancing a bioengineering research strategy to grow humanlike organs, these innovations are changing the practice of transplant medicine.

Safely Transplanting More Organs

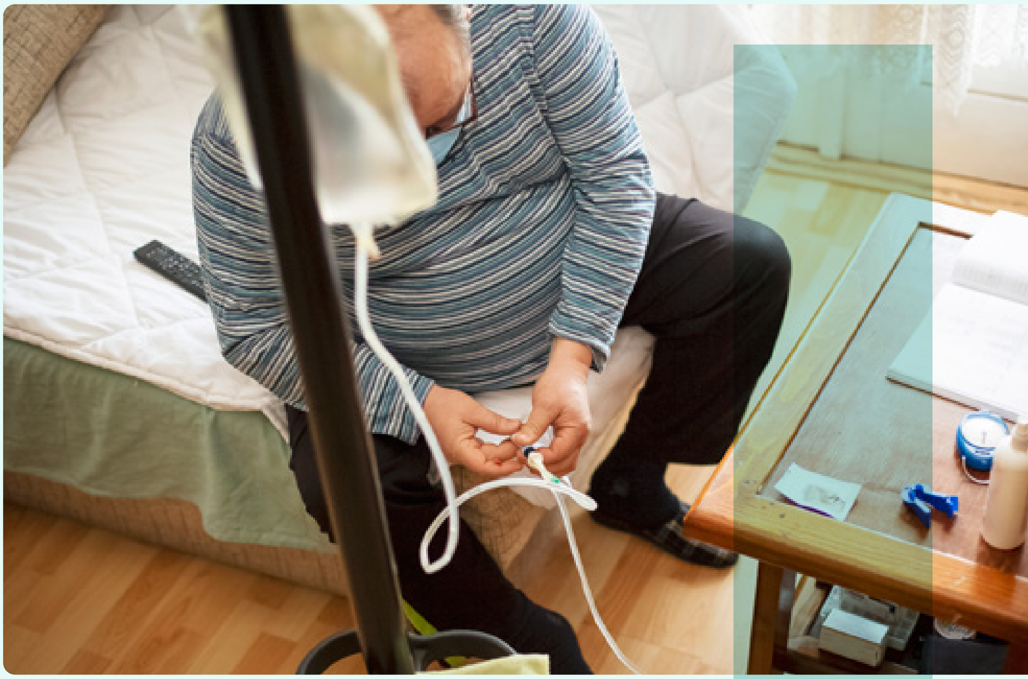
Mayo Clinic experts consider organ perfusion systems — mechanical devices that enable donated lungs, hearts, kidneys and livers to remain viable for longer — one of the biggest technological advances in transplantation. As an early adopter of this technology, Mayo Clinic surgeons are restoring organs that would otherwise not be safe for transplantation, meaning more patients have access to lifesaving organ transplants.

"Organ perfusion technology has helped us expand the donor pool and deliver transplants to more patients, all while maintaining some of the best patient outcomes," says Bashar A. Aqel, M.D.[3], director of the Arizona Transplant Center.

Palliative Care

If you choose not to have a kidney transplant or dialysis, you can choose palliative or supportive care to help you manage your symptoms and feel better. You also can combine palliative care with kidney transplant or dialysis.

Without either dialysis or a transplant, kidney failure progresses, eventually leading to death. Death can occur quickly or take months or years. Supportive care might include management of symptoms, measures to keep you comfortable and end-of-life planning.

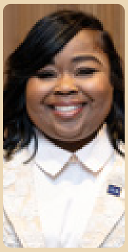


---

1. Information from this section was retrieved from the American Diabetes Association (https://www.diabetes.org/)
2. Information from this section was retrieved from the Mayo Clinic's website (https://www.mayoclinic.org/)
3. Bashar A. Aqel, M.D. (https://www.mayoclinic.org/biographies/aqel-bashar-a-m-d/bio-20055093)

TURNING TRIALS INTO TRIUMPH

A Journey with Kidney Disease



By Alethea Walls,
DPC Board Member

I've learned that living with kidney disease doesn't mean life stops - it just means you learn to live it differently.

My journey with kidney disease began at just 14 years old. I was diagnosed with rapidly progressive glomerulonephritis (RPGN), and my life changed overnight. While most teenagers were navigating high school and part-time jobs, I was learning about my treatment options. I started with peritoneal dialysis, then transitioned to hemodialysis. Each option came with its own adjustments, but I wasn't going to let this stop me. As soon as I turned 16, I got my first job and never stopped pushing forward. At one point, I was working 30 hours a week while balancing life with a chronic condition.

Right before I turned 19, I received my first kidney transplant. It was a moment of hope and a new kind of treatment altogether, but that transplant only lasted two years. I struggled with treatment compliance, trying desperately to feel "normal." That experience shaped me and ignited my passion for helping others, especially young patients. Understanding the importance of self-advocacy and consistent care is so critical, no matter which treatment path you're on. I began mentoring others through their own transitions into adulthood, teaching them that "normal" doesn't have to look like anyone else's version – whether you're on peritoneal dialysis, hemodialysis, or managing a transplant.

Later, my aunt stepped forward as a living donor and gave me my second kidney. It was a blessing that renewed my sense of purpose. I became a dialysis technician and eventually a preceptor, helping train the next generation of techs with an emphasis on patient-centered care. I knew the clinical side, and I knew the patient side. I understood how different treatment modalities worked because I was living both experiences.

But even with that second transplant, my kidneys began to fail again. I had to return to dialysis – this time, only in-center treatment was available to me initially, and I spent a month in the hospital. I was managing it while juggling multiple jobs and pursuing my love of hairstyling. Then came the Covid-19 pandemic - and with it, a devastating misdiagnosis that I had two years to live due to suspected multi-organ failure.

But God had other plans.

The diagnosis was later reversed, and I emerged with a renewed sense of gratitude and mission. Today, I'm back on dialysis and listed for another kidney transplant in Washington, D.C. I've been on dialysis for nearly 11 years this time. I continue to visit dialysis centers across metro Detroit, offering comfort, education, and reassurance to patients who, like me, have felt overwhelmed and alone. Many adults, especially after diagnosis, are scared and unsure about which treatment option is right for them. They're not always given the education they need about what's available. I advocate for them now, helping them understand their choices – just as I once did for younger patients.

In 2024, I was honored to be a DPC Patient Ambassador. I traveled to Washington, D.C., to share stories from the patient community, including my own, with lawmakers. That experience inspired me to run for a seat on the DPC Board of Directors, where I now proudly serve. Being elected to the board is one of the proudest moments of my life. I now walk in the footsteps of so many incredible patient leaders and carry their voices - alongside my own - into the rooms where decisions are made.

Through every high and low, I've learned that kidney disease doesn't define me. It fuels me. Every day I show up - to advocate, to educate, to comfort others - and to remind them that even through setbacks and transitions between different treatments, there's always a way forward.

I'm not just surviving. I'm living, giving, and proving that hope is always possible.

CHOOSING THE RIGHT PATH

My Journey with Home Hemodialysis

By Amber Gardner,
DPC Patient Ambassador

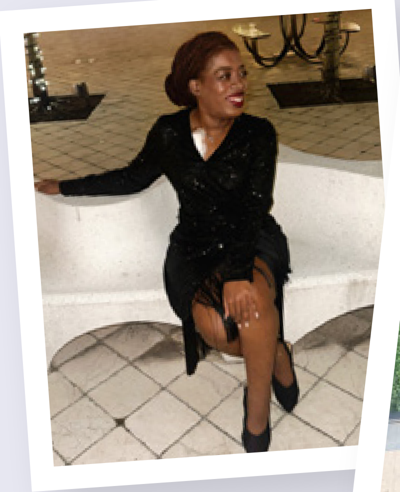
When I was diagnosed with kidney failure in 2023, it came as a shock. I had gone to the doctor for high blood pressure, but soon learned that my kidneys were failing. Suddenly, I was faced with decisions that would affect every part of my life – which treatment option to choose, how to adjust my routine, and what this diagnosis meant for my future.

With a background in journalism, research has always been second nature to me. I spent hours learning about dialysis – comparing hemodialysis (HD), done through the arm or a catheter, and peritoneal dialysis (PD), done through the stomach. I wanted to understand every detail before committing to a treatment. At first, I tried to delay dialysis while changing my diet and lifestyle, hoping to slow my disease's progression. But my body had other plans, and I soon found myself back in the hospital needing immediate treatment.

Shortly after, I began with in-center hemodialysis using a catheter. The adjustment was difficult, not only physically but emotionally. I struggled with the clinic environment, the rotating staff, lack of consistency, and occasional issues with training made it hard to feel comfortable. After experiencing an allergic reaction during one of my sessions, I knew I needed to find a different path.

Six months later, I transitioned to home dialysis. My mother became my legal caregiver, and it has made all the difference. Having a familiar face and steady hands manage my treatments has kept my catheter healthy and infection free. Home dialysis has given me back a sense of control. I can manage my schedule, create a comfortable environment, and focus on my wellbeing without the emotional strain of clinic visits.

The journey hasn't been easy. Shortly after my diagnosis, I had to resign from my teaching job. Without union protection or clear guidance about workplace accommodations, I didn't know my rights. My income dropped significantly when I moved from a salary to disability benefits, and I had to learn how to stretch every dollar. But through it all, I've found ways to maintain my quality of life, traveling when I can, and finding joy in the small things.



Now, I'm pursuing a living donor transplant to avoid the long wait. I've learned that being informed and proactive can make a world of difference. My advice for anyone newly diagnosed is simple: be your own advocate. Check your medical records, ask questions, and don't be afraid to research every option available. Know your legal rights at work and explore financial programs that can help you stay afloat.

Kidney failure changes your life, but it doesn't have to take it over. With the right support, information, and determination, you can find a treatment path that works for you. For me, that meant home hemodialysis, and the ability to live my life with more peace, confidence, and hope for what's next.

My Journey with Peritoneal Dialysis

By Dwan Dobson,
DPC Patient Ambassador

When I was first diagnosed with kidney failure in 2005, it felt like my life had been turned upside down overnight. One day I was working two jobs as a teacher and tutor at a detention center, and the next, I was in the hospital learning that my kidneys had stopped working. Like so many others, I didn't know what to expect, but I was determined to stay positive and keep moving forward.

At first, I began emergency dialysis through a chest port. Once I adjusted, I transitioned to peritoneal dialysis (PD) at home. PD gave me flexibility. I could continue teaching, mentoring, and doing what I loved, all while managing my treatments in a way that fit my lifestyle. In 2015, I was blessed to receive a kidney transplant. For nearly 10 years, that gift gave me a second chance at normalcy.

Unfortunately, in 2023, my transplanted kidney began to fail. I knew what that meant, it was time to start PD again. I began again in late 2024, and while the process wasn't easy, I reminded myself of the lessons I had learned: stay diligent, stay graceful, and keep living life. PD once again allows me to manage my treatments on my own schedule and maintain my independence while I wait for another transplant.

Even with dialysis, I've never let my condition hold me back. I've traveled to Dubai, gone on cruises, and visited Las Vegas all while on PD. The ability to order my supplies remotely has made it possible to keep exploring, though sometimes that means carrying boxes of supplies with me overseas. Most of my coworkers don't even know I'm on dialysis, I just focus on my work and keeping a positive outlook.

Finding a living donor hasn't been easy. Several friends and family members have tried to donate, but health issues like diabetes or low kidney function prevented it. Still, I remain hopeful. My faith and support of my community keep me grounded, and I'm on the transplant list again, ready for the next chapter.

I've also learned a lot about taking care of myself. When I reflect on my first transplant, I realize I wasn't always as consistent with my medications as I should have been. That experience taught me the importance of staying disciplined, taking medications on time, eating healthy, and monitoring phosphorous and fluid levels. These habits make all the difference.

For anyone newly diagnosed, my advice is simple: don't give up. Dialysis is not the end of your life, it's a way to keep living. Whether it's PD at home or in-center hemodialysis, find the treatment that fits your lifestyle and gives you the best quality of life. Stay positive, stay informed, and never be afraid to ask for help or share your story.

Kidney disease has taught me that attitude matters just as much as treatment. Every day I wake up thankful – for my care, my students, and the opportunities I still have to live life to the fullest. My journey isn't over yet, but I'm facing it head-on with hope, strength, and diligence.

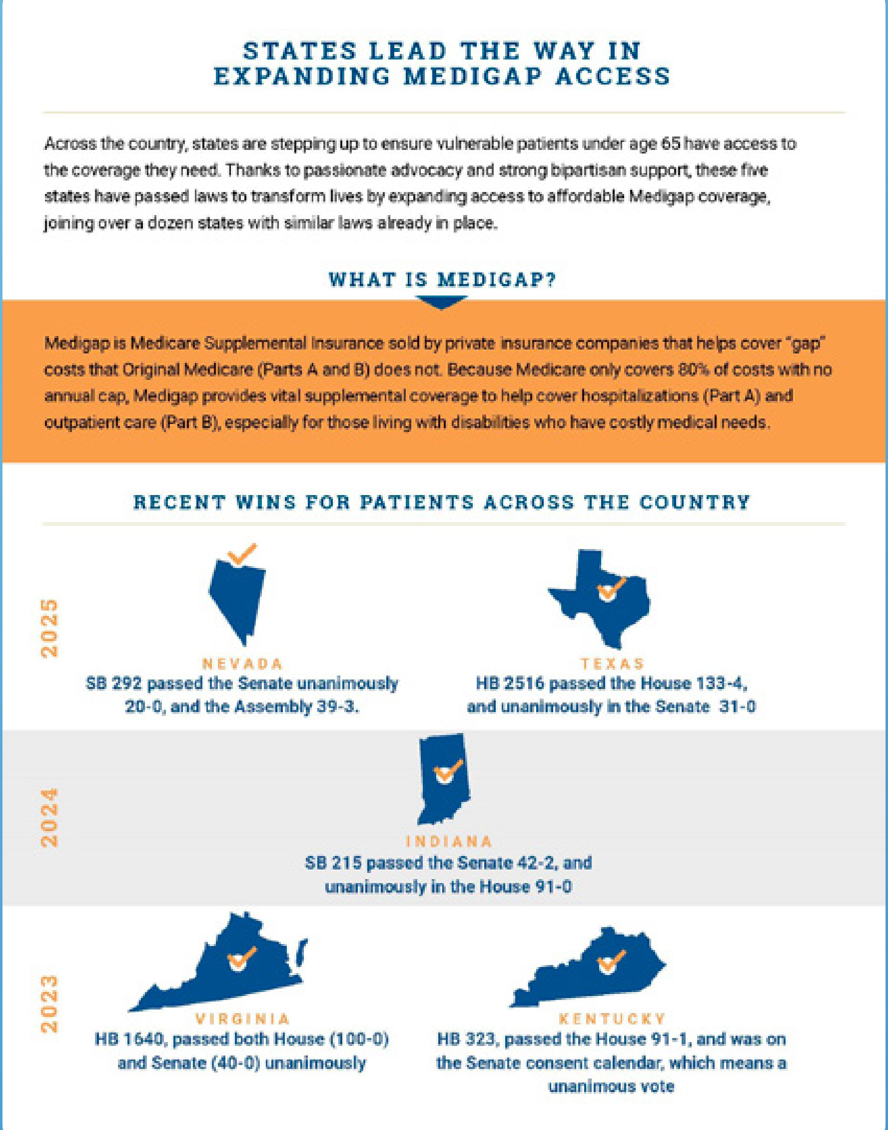
2025 State Medigap Wins & 2026 Priorities

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

DPC will continue to build on this momentum in the state Medigap arena in the 2026 legislative session. Our state advocacy directors are currently planning on advancing Medigap legislation in Georgia, Massachusetts, Michigan, Nebraska, Ohio, and Utah.

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/).



STATES LEAD THE WAY IN EXPANDING MEDIGAP ACCESS

Across the country, states are stepping up to ensure vulnerable patients under age 65 have access to the coverage they need. Thanks to passionate advocacy and strong bipartisan support, these five states have passed laws to transform lives by expanding access to affordable Medigap coverage, joining over a dozen states with similar laws already in place.

WHAT IS MEDIGAP?

Medigap is Medicare Supplemental Insurance sold by private insurance companies that helps cover "gap" costs that Original Medicare (Parts A and B) does not. Because Medicare only covers 80% of costs with no annual cap, Medigap provides vital supplemental coverage to help cover hospitalizations (Part A) and outpatient care (Part B), especially for those living with disabilities who have costly medical needs.

RECENT WINS FOR PATIENTS ACROSS THE COUNTRY

2025

NEVADA
SB 292 passed the Senate unanimously 20-0, and the Assembly 39-3.

TEXAS
HB 2516 passed the House 133-4, and unanimously in the Senate 31-0

2024

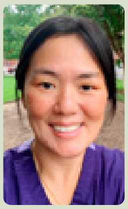
INDIANA
SB 215 passed the Senate 42-2, and unanimously in the House 91-0

2023

VIRGINIA
HB 1640, passed both House (100-0) and Senate (40-0) unanimously

KENTUCKY
HB 323, passed the House 91-1, and was on the Senate consent calendar, which means a unanimous vote

Kidney-Friendly Recipe



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 a recipe that would be a quick and delicious addition to any holiday dinner!

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 Educativo y dietista titulada que trabaja con personas en todas las etapas de la enfermedad renal, por proporcionarnos una receta que sería un complemento rápido y delicioso para cualquier cena festiva.

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.*

Parmesan Roasted Green Beans

Submitted By **JoEllen Ford, MS, RD, LDN**

Prep Time: 00:05
Cook Time: 00:15
Total Time: 00:20

Ingredients

Makes 4 Servings

- 1 lb. fresh green beans
- 2 T. olive oil 2 T. grated parmesan cheese
- 2 T. panko bread crumbs
- ¼ tsp. salt
- ½ tsp. garlic powder

Instructions

Preheat oven to 400°. Combine all ingredients in a large mixing bowl; toss to coat. Spread green beans on a large rimmed baking sheet. Roast for 15-20 minutes; stirring halfway through.

Nutrition Facts (Per Serving)

- Sodium: 244 mg
- Potassium: 120 mg
- Phosphorus: 16 mg

Habichuelas tiernas horneadas con parmesano

Receta enviada por **JoEllen Ford, MS, RD, LDN**

Tiempo de preparación: 5 min
Tiempo de cocción: 15 min
Tiempo total: 20 min

Ingredientes

Porciones: 4

- 1 libra (aprox. 450 g) habichuelas tiernas (o judías verdes) frescas
- 2 cucharadas aceite de oliva
- 2 cucharadas queso parmesano rallado
- 2 cucharadas pan rallado japonés (panko)
- ¼ cucharadita sal
- ½ cucharadita ajo en polvo

Instrucciones

Precaliente el horno a 400 °F (200 °C). En un tazón grande, mezcle todos los ingredientes hasta que las habichuelas tiernas (o judías verdes) estén bien cubiertas con el resto de los ingredientes. Distribuya las habichuelas o judías en una bandeja para hornear con bordes. Hornee por 15-20 minutos, revolviendo a la mitad del tiempo de cocción.

Información Nutricional (por porción):

- Sodio: 244 mg
- Potasio: 120 mg
- Fósforo: 16 mg

DPC
EDUCATION
CENTER

1300 17th Street N, Suite #580
Arlington, VA 22209

NON PROFIT ORG
US POSTAGE
PAID
SEATTLE, WA
PERMIT NO 2389

Happy Holidays

From DPC and the DPC Education Center's Board, staff, and volunteers, we would like to wish you and your loved ones a warm and happy holiday season. Thank you for being a part of and continuing to help grow our organizations and being a voice for kidney patients nationwide.

Board Members and Advisory Council

DPC
EDUCATION
CENTER

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

DPC
EDUCATION
CENTER

issue number 22

Board Members and Advisory Council