issue number 23

The Kidney Citizen

DPC EDUCATION CENTER

A publication of Dialysis Patient Citizens (DPC) Education Center

INNOVATION & EMPOWERMENT

President's Message

As I reflect on this issue of The Kidney Citizen, I'm reminded of the powerful role innovation plays in each of our journeys with kidney disease. Innovation is not just about new technology. It's about possibility. It motivates patients, inspires hope, and reminds us that better outcomes are within reach.

When I began dialysis, I was balancing work, family, and the physical and emotional toll of treatment. Like many patients, I had to make difficult adjustments, but I was determined to keep moving forward. What made the biggest difference was staying engaged, leaning on my support system, and taking an active role in understanding my care. I didn't want to just go through treatment; I wanted to take control of it.

That perspective shapes how I think of innovation today. We are seeing promising advancements, including a new type of dialysis machine gaining traction in Europe that is improving how effectively toxins are removed from the blood. There is also progress in managing phosphorus levels, preventing infections, and treating anemia. These are all important steps that make treatment safer and more manageable for patients.

But innovation isn't only about technology. It's also about empowerment. It's about asking questions, seeking knowledge, and advocating for ourselves and others. That mindset helped carry me through my own journey and continues to guide my work today.

What all of this creates, above all else, is optimism. It reminds us that today's challenges do not define tomorrow's possibilities. Each new development, and each patient who finds their voice, brings us closer to a future where living well with kidney disease is the expectation, not the exception.

I encourage you to get even more involved with our affiliate, Dialysis Patient Citizens. Along with the DPC Education Center, it remains committed to supporting and advocating for continued innovation in kidney care. Because when innovation thrives, patients thrive – and that's what drives us forward.

Thank you for being part of this community and for continuing to inspire change through your resilience, your voice, and your unwavering hope.

Sincerely,

Merida Bourjolly,
President of DPC Education Center Board of Directors

CEO's Message

Thank you for reading the 23rd issue of the Dialysis Patient Citizens Education Center's magazine, The Kidney Citizen.

For more than two decades, Dialysis Patient Citizens (DPC) has remained committed to one central mission: ensuring that patients have a powerful voice in the policies and decisions that shape their care. As the nation's largest patient-led dialysis organization, we continue to stand alongside the more than half a million Americans living with kidney failure – amplifying your experiences, your needs, and your vision for a better future.

This issue's theme, Innovation and Empowerment, speaks to both the urgency of this moment and the opportunity ahead. While there have been meaningful advances in kidney care, it is clear that far more innovation is needed – especially when it comes to improving patient outcomes, expanding treatment options, and modernizing the systems that support care delivery. Patients deserve not only better therapies, but also a healthcare system that keeps up with their needs.

One area where change is especially vital is the current payment system, which too often falls short in supporting innovation and patient-centered care. Reforming this flawed system is essential to unlocking new solutions and ensuring that patients have access to the best possible treatments. At DPC, we are committed to shining a light on these challenges and working with policymakers to drive meaningful change.

But real change doesn't happen without action, and that's where your voice matters most. Through kidneyaction.org, patients, caregivers, and advocates can connect directly with members of Congress to share their stories and push for policies that prioritize innovation and equity in kidney care. Advocacy is not just part of our mission. It's the engine that drives progress.

As you read through this issue, I encourage you to see yourself as part of that movement. Each of us has a role to play in leading the charge toward a more innovative, equitable, and patient-centered future. Together, we can challenge the status quo, elevate patient voices, and help shape a system that truly works for everyone.

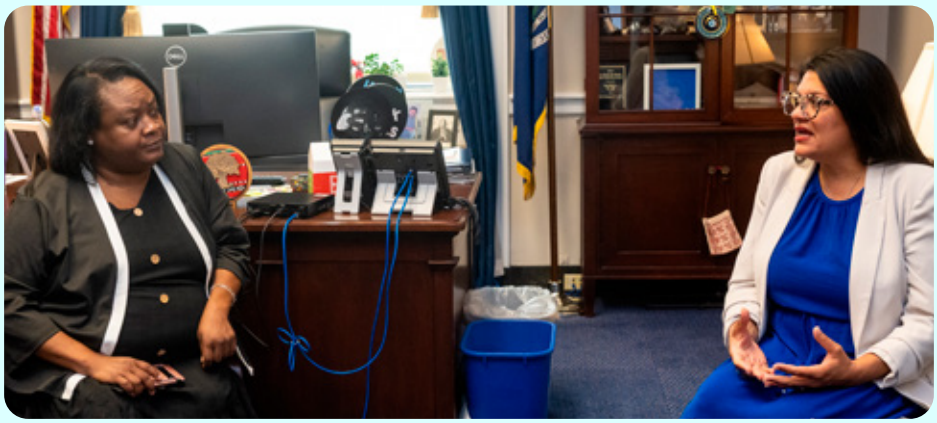
Thank you for your continued commitment to this community – for speaking up, staying engaged, and pushing forward. The future of kidney care depends on all of us, and I am proud to stand with you as we lead the way.

Sincerely,

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

LIVING WITH PURPOSE

My Journey of Strength, Advocacy, and Hope



By Quiana Bishop,
DPC Board President

Ten years ago, I found myself stepping into a dialysis center for the first time. I was uncertain, overwhelmed, and scared. Kidney failure had suddenly become part of my story. But from day one, I made a decision: this diagnosis would not define me. I was going to keep living and keep finding joy wherever I could.

I was raised in Chicago and now call Detroit home. My journey with kidney disease is deeply personal - not just because I live with it, but because I watched my father battle it too. He was on dialysis and received multiple kidney transplants. I learned what resilience looked like. I'd like to think he's watching me now with pride, seeing me fight for others the way I saw him fight every day.

I once worked as a teacher, with a special love for guiding infants in the classroom. It was more than a job - it was a calling. While my health eventually made it difficult to stay in that role, I never stopped nurturing. These days, that nurturing comes through advocacy, compassion, and connection with those in the dialysis community.

One of the hardest days of my journey came when I learned I wasn't eligible for a transplant due to additional medical complications. It felt like a door slamming shut, but I refused to see it as the end. "My life doesn't end there," I told myself. "Every day I wake up is a chance to make something meaningful happen." And I've tried to do just that.

As a single mom to a soon to be 21-year-old son, my motivation is personal and powerful. He has been my strength, my laughter, my reason. Managing dialysis while raising a child hasn't been easy, but it's made every milestone even more meaningful.

Joining the Board of Directors at Dialysis Patient Citizens (DPC) changed my life. Suddenly, I wasn't just a patient - I was a voice. A leader. An advocate. Through DPC, I've been able to share my story with lawmakers and help push for better policies for people like me. It's reminded me that our lived experiences have the power to change lives - and laws. When patients speak up, people listen.

People often assume dialysis is something you plan for - but it's not. It happens fast. You get the diagnosis, and within days, you're facing machines, needles, and a mountain of paperwork. The system is confusing. The costs are crushing. And the emotional toll can be just as heavy as the physical one. That's why advocating for patients is so important to me. Any option that gives patients more stability, more support, and more choices should be on the table. What patients need most in those moments is time, support, and clear information, not roadblocks.

However, I choose to stay hopeful. I show up. I speak out. I've testified, written letters, and joined awareness events. I tell lawmakers: put yourself - or someone you love - in my shoes. Imagine managing a life-threatening illness while struggling to afford care or make sense of it all. Then ask yourself what kind of support you'd want to have.

I want people to understand that we are more than our diagnosis. We are parents, workers, caregivers, advocates. We are living, breathing proof that a full life is still possible on dialysis.

To anyone just starting this journey:
you're not alone. You are strong.
And your voice matters.

Kidney failure may be a part of my life, but it is not the end of my story. It is the reason I found a new voice. It is why I advocate. It is how I've discovered, every day, what it means to live with a purpose.

High-Volume Hemodiafiltration

Understanding a Dialysis Treatment Approach

Dr. Stefano Stuard, MD, PhD, Nephrologist; **and Dr. Michael Anger,** MD, Nephrologist

- Hemodiafiltration (HDF) is a type of dialysis that cleans the blood using two cleaning processes: diffusion and convection. Standard hemodialysis mainly relies on diffusion alone.
- Diffusion and convection remove waste in different ways. Diffusion helps remove smaller waste products, while convection helps move larger waste substances out of the blood. Using both processes allows for a broader range of waste removal during treatment.
- High-volume hemodiafiltration refers to HDF treatments that use a larger amount of clean, sterile replacement fluid during the dialysis session, as described in clinical studies. This fluid is carefully prepared and monitored.
- HDF does not change how long a dialysis session lasts. The treatment time is similar to standard hemodialysis. The main difference is how the blood is cleaned, not the length of the session.
- HDF is available in some dialysis centers. Not all patients receive the same type of dialysis. The choice of treatment depends on individual health needs, equipment availability, and clinical judgment, and should be discussed with the dialysis care team.

Kidney Function and the Need for Dialysis

Healthy kidneys do many important jobs. They clean the blood by removing waste products and extra water. They help keep the right balance of salts and minerals in the body. Kidneys also help control blood pressure, keep bones healthy, and help the body make red blood cells.

When the kidneys stop working well, waste products and fluid build up in the blood. This can cause swelling, feeling tired, shortness of breath, and a general feeling of not being well. Dialysis is a treatment that helps do some of the work of the kidneys. It does not replace everything healthy kidneys do, but it helps remove waste and extra fluid from the blood.

Standard Hemodialysis

Most people in the United States with kidney failure receive standard hemodialysis (HD). This treatment can be done in a dialysis clinic and, for some people, at home.

During HD, blood is taken out of the body through a tube and passed through a filter called a dialyzer. Inside the dialyzer, waste products move from the blood into a special cleaning fluid (dialysate). The cleaned blood is then returned to the body.

HD removes many small waste products from the blood. However, kidney failure can also lead to the buildup of larger waste substances. These larger wastes may be harder to remove and can stay in the body longer.

Over time, kidney failure and the need for ongoing dialysis can be linked to inflammation, changes in blood pressure during treatment, effects on the heart, and changes in thinking, such as memory or concentration problems. This may help explain why some people continue to feel unwell even when they attend all scheduled dialysis treatments.

Hemodiafiltration: An Alternative Dialysis Method

Hemodiafiltration (HDF) is a type of dialysis that cleans the blood using two processes instead of one (1). HD mainly uses a process called diffusion. With diffusion, waste moves from the blood into the cleaning fluid because there is more waste in the blood than in the fluid (Figure 1). HDF uses diffusion and another process called convection. Convection uses a controlled movement of fluid to help carry waste products

out of the blood. This process helps move some waste substances that do not move easily with diffusion alone, including some larger wastes.

By using both diffusion and convection, HDF is designed to remove different types of waste products from the blood (1). HDF has been used for many years in other parts of the world and is available in some dialysis centers in the United States.

Meaning of High-Volume Hemodiafiltration

The term "high-volume" (HV) refers to the amount of extra cleaning fluid used during a dialysis treatment (2). In high-volume hemodiafiltration (HVHDF), clinical studies describe the use of more than 23 liters of sterile replacement fluid during a single dialysis session (2).

This sterile fluid is added to the blood during treatment and removed at the same time through the dialysis filter as part of the cleaning process.

The extra fluid is removed and does not remain in the body after treatment.

Evidence from Clinical Studies

HDF and HVHDF have been studied in many clinical trials and large studies that look at how treatments are used in everyday care. These studies have been done in Europe, Asia, Australia, and Latin America (2–22).

In some large groups of patients, HVHDF was associated with differences in certain outcomes over time (2, 4–6, 8, 9, 21, 23–27). These included measures related to survival, hospital use, heart-related outcomes, and overall well-being. Studies that looked at routine clinical practice reported similar observations in some patient populations (10–14, 16, 17, 19–22). Hospital stays can be influenced by many factors, such as age, other medical conditions, type of dialysis access, and local care practices. One large international study also reported differences in hospital stays among patients treated with HVHDF in some settings (27). These results describe what was observed in groups of patients and do not guarantee the same results for every individual.

Effects During Dialysis Sessions

For many people, the dialysis session itself can be difficult. Sudden drops in blood pressure during treatment can cause dizziness, nausea, muscle cramps, headaches, or feeling very tired after dialysis.

In some clinical studies, patients treated with HDF were observed to have different blood pressure patterns during dialysis compared with patients receiving HD (3, 7, 28–30). Some studies also reported differences in muscle cramping during treatment (1, 7, 26, 31). HDF uses very clean dialysis fluid and adds sterile fluid during the session. In some studies, differences were seen in measured markers related to inflammation between patient groups (1, 32–34).

The length of the dialysis session is usually the same as with HD. The main difference is how the blood is cleaned, not how long the patient is connected to the machine.

Effects Between Treatments and Daily Life

Some patients notice changes between dialysis treatments, not just during the session. In some studies, patients treated with HVHDF reported differences in appetite, energy, or daily activities (35–36). Other studies reported differences in joint or muscle symptoms, such as stiffness or discomfort, in some patient groups (1, 37).

Some patients who switched from HD to HVHDF reported differences in movement or comfort during everyday activities (38). Other studies reported differences in physical activity or physical function over time in groups of patients (23, 26, 39).

Some people also reported differences in how they felt between treatments or in their ability to take part in social activities, such as spending time with family and friends (23, 39). Experiences vary, and not all patients notice the same changes.

Infections and Immune Health

People with kidney failure often have a weaker immune system. Infection risk can be affected by many factors, including overall health, dialysis access type, and care practices. Infections are a common reason for hospitalization among dialysis patients.

Some large clinical and observational studies reported differences in infection-related outcomes, including hospital use related to infections, in some settings (2, 9, 21, 27, 30, 32, 39, 40).

Some studies also reported differences in measured immune responses after vaccines, such as influenza or COVID-19 vaccines, among patient groups (41).

Cardiovascular Health

Heart disease is a leading cause of death in people receiving dialysis. Over time, waste buildup in the blood, inflammation, and changes in blood pressure during treatment can place stress on the heart.

In some studies, HVHDF was associated with differences in certain body measurements related to heart function (43). Differences in heart-related events and hospital use were also reported between patient groups in some settings (2, 8, 9, 21, 27, 40).

Anemia and Energy Levels

Anemia, which means having a low number of red blood cells, is common in people with kidney failure. Anemia can cause tiredness, shortness of breath, and low energy.

Some studies reported differences in the use of medications to treat anemia between patient groups treated with HDF and HD (1, 30, 44, 45). Treatment needs are decided by the dialysis care team and may change over time.

Some patients may notice differences in energy levels or medication use, while others may not. Experiences vary from person to person.

Safety and Availability

When performed with modern equipment, clean water systems, and trained staff, HDF has been used in dialysis centers around the world. As with any dialysis treatment, possible risks include low blood pressure, muscle cramps, access problems, and infection.

All dialysis treatments in the United States, including HD and HDF, follow strict safety and water quality standards. Not all dialysis centers offer HVHDF. Availability may change as clinics update equipment, water systems, and staff training.

Choosing the Right Treatment

HVHDF is not a cure for kidney failure. Dialysis will continue to be part of daily life.

HVHDF is one dialysis approach that may be considered by some patients. It cleans the blood using a different method than HD. Possible effects depend on a person's health, dialysis access, and treatment goals.

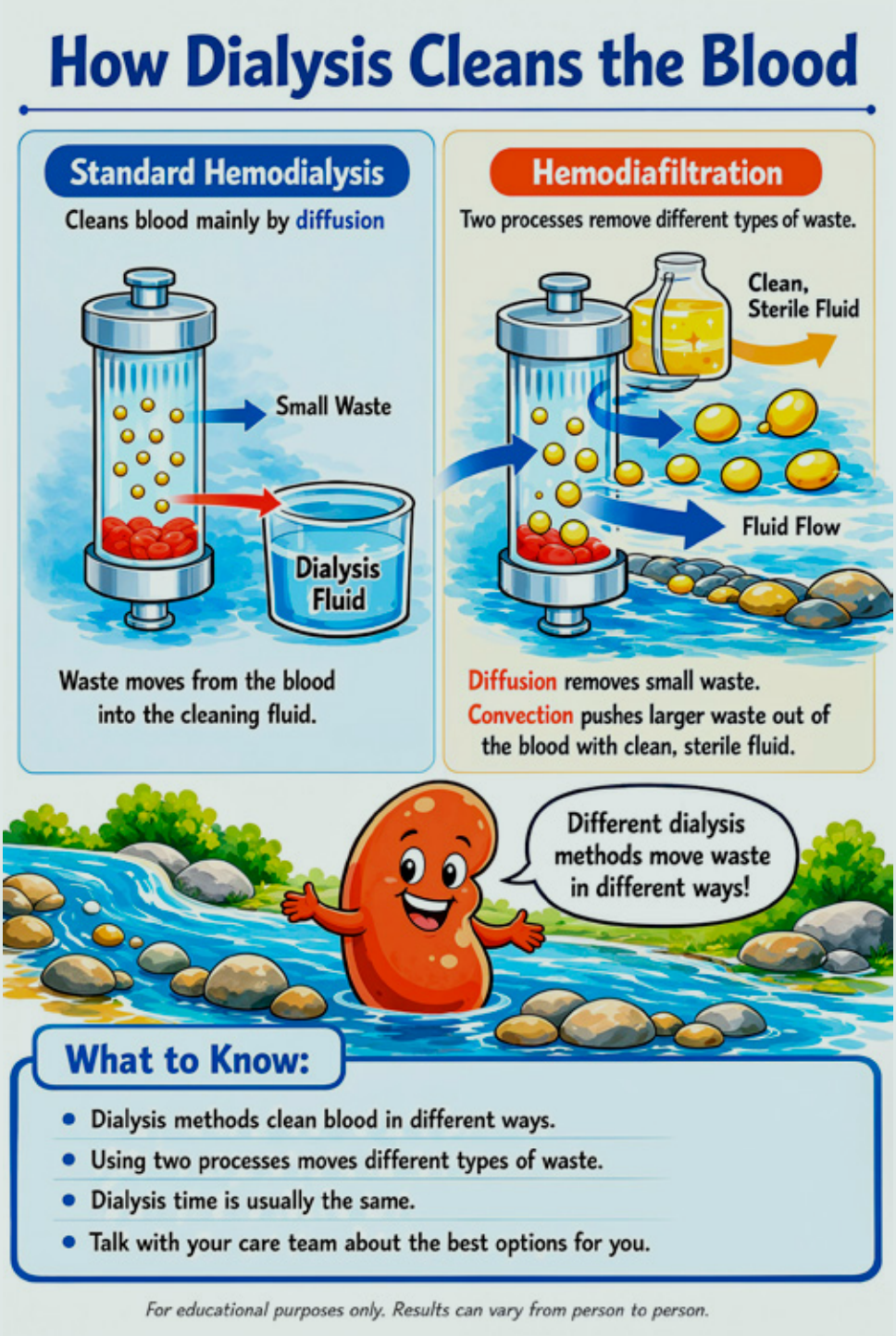


Figure 1

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Patients are encouraged to talk with their doctor and dialysis care team about all treatment options to decide what is best for them.

Educational Statement:

This document is provided for educational purposes only. It is intended to give general information and does not describe all possible risks or benefits

of dialysis treatments. The information summarized here is based on published studies and may not apply to every person. This material is not intended to replace medical advice or to promote any specific product or device. Treatment decisions should always be made together with a qualified healthcare professional.

Role and Affiliation

Dr. Stefano Stuard is Senior Vice President, Global Clinical Officer for Hemodiafiltration, Fresenius Medical Care, Global Medical Office.

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These roles are listed for transparency only and do not imply endorsement, promotion, recommendation, or comparative evaluation of any dialysis treatment, product, or device.

Reference

1. Stuard S, Maddux FW, Canaud B. Why High-Volume Post-Dilution Hemodiafiltration Should Be the New Standard in Dialysis Care: A Comprehensive Review of Clinical Outcomes and Mechanisms. J Clin Med. 2025;14(14).
2. Blankestijn PJ, Vernooij RWM, Hockham C, Strippoli GFM, Canaud B, Hegbrant J, et al. Effect of Hemodiafiltration or Hemodialysis on Mortality in Kidney Failure. N Engl J Med. 2023;389(8):700-9.
3. Locatelli F, Altieri P, Andrulli S, Bolasco P, Sau G, Pedrini LA, et al. Hemofiltration and hemodiafiltration reduce intradialytic hypotension in ESRD. J Am Soc Nephrol. 2010;21(10):1798-807.
4. Grooteman MP, van den Dorpel MA, Bots ML, Penne EL, van der Weerd NC, Mazairac AH, et al. Effect of online hemodiafiltration on all-cause mortality and cardiovascular outcomes. J Am Soc Nephrol. 2012;23(6):1087-96.
5. Ok E, Asci G, Toz H, Ok ES, Kircelli F, Yilmaz M, et al. Mortality and cardiovascular events in online haemodiafiltration (OL-HDF) compared with high-flux dialysis: results from the Turkish OL-HDF Study. Nephrol Dial Transplant. 2013;28(1):192-202.
6. Maduell F, Moreso F, Pons M, Ramos R, Mora-Macia J, Carreras J, et al. High-efficiency postdilution online hemodiafiltration reduces all-cause mortality in hemodialysis patients. J Am Soc Nephrol. 2013;24(3):487-97.
7. Morena M, Jaussent A, Chalabi L, Leray-Moragues H, Chenine L, Debure A, et al. Treatment tolerance and patient-reported outcomes favor online hemodiafiltration compared to high-flux hemodialysis in the elderly. Kidney Int. 2017;91(6):1495-509.
8. Peters SA, Bots ML, Canaud B, Davenport A, Grooteman MP, Kircelli F, et al. Haemodiafiltration and mortality in end-stage kidney disease patients: a pooled individual participant data analysis from four randomized controlled trials. Nephrol Dial Transplant. 2016;31(6):978-84.
9. Vernooij RWM, Hockham C, Strippoli G, Green S, Hegbrant J, Davenport A, et al. Haemodiafiltration versus haemodialysis for kidney failure: an individual patient data meta-analysis of randomised controlled trials. Lancet (London, England). 2024;404:1742-9.
10. Imamovic G, Hrvacevic R, Kapun S, Marcelli D, Bayh I, Grassmann A, et al. Survival of incident patients on high-volume online hemodiafiltration compared to low-volume online hemodiafiltration and high-flux hemodialysis. International urology and nephrology. 2014;46(6):1191-200.
11. Canaud B, Barbieri C, Marcelli D, Bellocchio F, Bowry S, Mari F, et al. Optimal convection volume for improving patient outcomes in an international incident dialysis cohort treated with online hemodiafiltration. Kidney Int. 2015;88(5):1108-16.
12. Neri L, Gurevich K, Zarya Y, Plavinskii S, Bellocchio F, Stuard S, et al. Practice Patterns and Outcomes of Online Hemodiafiltration: A Real-World Evidence Study in a Russian Dialysis Network. Blood purification. 2021;50(3):309-18.
13. Canaud B, Bragg-Gresham JL, Marshall MR, Desmeules S, Gillespie BW, Depner T, et al. Mortality risk for patients receiving hemodiafiltration versus hemodialysis: European results from the DOPPS. Kidney Int. 2006;69(11):2087-93.
14. Canaud B, Bayh I, Marcelli D, Ponce P, Merello JI, Gurevich K, et al. Improved survival of incident patients with high-volume haemodiafiltration: a propensity-matched cohort study with inverse probability of censoring weighting. Nephron. 2015;129(3):179-88.
15. Maduell F, Varas J, Ramos R, Martin-Malo A, Perez-Garcia R, Berdud I, et al. Hemodiafiltration reduces all-cause and cardiovascular mortality in incident hemodialysis patients: a propensity-matched cohort study. American Journal of Nephrology. 2017;46(4):288-97.
16. Kikuchi K, Hamano T, Wada A, Nakai S, Masakane I. Predilution online hemodiafiltration is associated with improved survival compared with hemodialysis. Kidney Int. 2019;95(4):929-38.
17. Mercadal L, Franck JE, Metzger M, Urena Torres P, de Cornelissen F, Edet S, et al. Hemodiafiltration Versus Hemodialysis and Survival in Patients With ESRD: The French Renal Epidemiology and Information Network (REIN) Registry. Am J Kidney Dis. 2016;68(2):247-55.
18. See EJ, Hedley J, Agar JWM, Hawley CM, Johnson DW, Kelly PJ, et al. Patient survival on haemodiafiltration and haemodialysis: a cohort study using the Australia and New Zealand Dialysis and Transplant Registry. Nephrol Dial Transplant. 2019;34(2):326-38.
19. Valderrama LA, Barrera L, Cantor EJ, Muñoz J, Arango J, Tobon C, et al. Mortality in High-Flux Hemodialysis vs. High-Volume Hemodiafiltration in Colombian Clinical Practice: A Propensity Score Matching Study. Kidney and Dialysis. 2022;2(2):209-20.

20. da Rocha EP, Kojima CA, Modelli de Andrade LG, Costa DM, Magalhaes AO, Rocha WF, et al. Comparing Survival Outcomes between Hemodialysis and Hemodiafiltration Using Real-World Data from Brazil. Journal of Clinical Medicine. 2024;13(2):594.

21. Zhang Y, Winter A, Ferreras BA, Carioni P, Arkossy O, Anger M, et al. Real-world effectiveness of hemodialysis modalities: a retrospective cohort study. BMC Nephrology. 2025;26(1):1-9.

22. Strogoff-de-Matos JP, Canziani MEF, Barra ABL. Mortality on Hemodiafiltration Compared to High-Flux Hemodialysis: A Brazilian Cohort Study. Am J Kidney Dis. 2025.

23. Rose M, Fischer FH, Liegl G, Strippoli GFM, Hockham C, Vernooij RWM, et al. The CONVINCE randomized trial found positive effects on quality of life for patients with chronic kidney disease treated with hemodiafiltration. Kidney Int. 2024;106(5):961-71.

24. Pecoits-Filho R, Larkin J, Poli-de-Figueiredo CE, Cuvello-Neto AL, Barra ABL, Goncalves PB, et al. Effect of hemodiafiltration on measured physical activity: primary results of the HDFIT randomized controlled trial. Nephrol Dial Transplant. 2021;36(6):1057-70.

25. Han M, Guedes M, Larkin J, Raimann JG, Lesqueves Barra AB, Canziani MEF, et al. Effect of Hemodiafiltration on Self-Reported Sleep Duration: Results from a Randomized Controlled Trial. Blood purification. 2020;49(1-2):168-77.

26. Karkar A, Abdelrahman M, Locatelli F. A Randomized Trial on Health-Related Patient Satisfaction Level with High-Efficiency Online Hemodiafiltration versus High-Flux Dialysis. Blood purification. 2015;40(1):84-91.

27. Zhang Y, Winter A, Ficociello LH, Ferrera BA, Carioni P, Apel C, et al. Real-World Hospitalization Outcomes with On-Line Hemodiafiltration Versus High-Flux Hemodialysis: A Retrospective, International Cohort Study. Clin J Am Soc Nephrol. 2025.

28. Sande FMV, Kooman JP, Konings CJ, Leunissen KML. Thermal effects and blood pressure response during postdilution hemodiafiltration and hemodialysis: the effect of amount of replacement fluid and dialysate temperature. J Am Soc Nephrol. 2001;12(9):1916-20.

29. Donauer J, Schweiger C, Rumberger B, Krumme B, Bohler J. Reduction of hypotensive side effects during online-haemodiafiltration and low temperature haemodialysis. Nephrol Dial Transplant. 2003;18(8):1616-22.

30. Stuard S, Maddux FW. High-Volume Hemodiafiltration: Expanding the Evidence Beyond Randomized Trials-A Critical Perspective on the 2025 EuDial Consensus. J Clin Med. 2025;14(9).

31. Guedes M, Vernooij RWM, Davenport A, Kuhlmann MK, Aregger F, Pecoits-Filho R. Clinical performance, intermediate and long-term outcomes of high-volume hemodiafiltration in patients with kidney failure. Semin Dial. 2022;35(5):420-6.

32. Ward RA, Schmidt B, Hullin J, Hillebrand GF, Samtleben W. A comparison of on-line hemodiafiltration and high-flux hemodialysis: a prospective clinical study. J Am Soc Nephrol. 2000;11(12):2344-50.

33. den Hoedt CH, Bots ML, Grooteman MP, van der Weerd NC, Mazairac AH, Penne EL, et al. Online hemodiafiltration reduces systemic inflammation compared to low-flux hemodialysis. Kidney Int. 2014;86(2):423-32.

34. Filiopoulos V, Hadjiyannakos D, Metaxaki P, Sideris V, Takouli L, Anogiati A, et al. Inflammation and oxidative stress in patients on hemodiafiltration. Am J Nephrol. 2008;28(6):949-57.

35. Canaud B, Strippoli G, Davenport A. High-Volume Hemodiafiltration Versus High-Flux Hemodialysis: A Narrative Review for the Clinician. J Clin Med. 2025;14(8).

36. Molina P, Vizcaino B, Molina MD, Beltran S, Gonzalez-Moya M, Mora A, et al. The effect of high-volume online haemodiafiltration on nutritional status and body composition: the ProtEin Stores prEservaTion (PESET) study. Nephrol Dial Transplant. 2018;33(7):1223-35.

37. Pedreros-Rosales C, Jara A, Lorca E, Mezzano S, Pecoits-Filho R, Herrera P. Unveiling the Clinical Benefits of High-Volume Hemodiafiltration: Optimizing the Removal of Medium-Weight Uremic Toxins and Beyond. Toxins (Basel). 2023;15(9).

38. Maeda K, Kobayakawa H, Fujita Y, Takai I, Morita H, Emoto Y, et al. Effectiveness of push/pull hemodiafiltration using large-pore membrane for shoulder joint pain in long-term dialysis patients. Artif Organs. 1990;14(5):321-7.

39. Battaglia Y, Shroff R, Meijers B, Nistor I, Alfano G, Franssen C, et al. Haemodiafiltration versus high-flux haemodialysis - a Consensus Statement from the EuDial Working Group of the ERA. Nephrol Dial Transplant. 2025.

40. Rootjes PA, Grooteman MPC, Budding AE, Bontkes HJ, Wijngaarden G, Nube MJ, et al. Randomized Trial Demonstrating No Translocation of Intact Intestinal Bacteria During Hemodialysis or Hemodiafiltration. Kidney Int Rep. 2025;10(1):109-19.

41. Carrera F, Jacobson SH, Costa J, Marques M, Ferrer F. Better Anti-Spike IgG Antibody Response to SARS-CoV-2 Vaccine in Patients on Haemodiafiltration than on Haemodialysis. Blood purification. 2023;52(6):600-8.

42. Canaud B, Blankestijn PJ, Grooteman MPC, Davenport A. Why and how high volume hemodiafiltration may reduce cardiovascular mortality in stage 5 chronic kidney disease dialysis patients? A comprehensive literature review on mechanisms involved. Semin Dial. 2022;35(2):117-28.

43. Malyszko J, Malyszko JS, Kozminski P, Mysliwiec M. Type of renal replacement therapy and residual renal function may affect prohepcidin and hepcidin. Ren Fail. 2009;31(10):876-83.

44. Bolasco PG, Ghezzi PM, Serra A, Corazza L, Murtas S, Mascia M, et al. Hemodiafiltration with endogenous reinfusion with and without acetate-free dialysis solutions: effect on ESA requirement. Blood purification. 2011;31(4):235-42.

Innovation Isn't Enough

A Dialysis Patient's Case for Real Access

By Pesh Patel,
DPC Patient Ambassador

In 2017, I was visiting Melbourne, Australia as part of my career as a global hospitality executive. While walking around the city, I suddenly had to stop four separate times over the course of just three city blocks because I couldn't breathe. I thought I was out of shape. What I didn't know was that I had been living with a single kidney since birth, and that kidney was functioning at 2%. If I hadn't gone to the ER when I did, I would have died within 20 hours. Two hours later, I was in the ICU on a 24-hour dialysis machine. It was the first time I had ever heard the word "transplant" outside of a movie.

I started hemodialysis in Australia and continued in-center treatment when I returned to the United States. Fifteen months later, on August 7, 2018, I received a kidney transplant. However, two and a half years later, my body rejected the kidney. I was diagnosed with antibody-mediated rejection combined with BK virus, a cruel combination because treating one condition can worsen the other. Despite every effort, the transplant couldn't be saved. By August 2024, I was back on dialysis.

My care team insisted I get a fistula. I said no. Instead I chose to keep my catheter and manage the risks carefully. I became meticulous about protection. I kept every surface clean, followed every protocol, and stayed vigilant at every treatment session.

That's why, when I attended the American Society of Nephrology Kidney Week conference in October 2024, a chance encounter changed everything. I was introduced to DefenCath, an antimicrobial lock solution (CLS) that reduces the risk of catheter-related bloodstream infections (CRBSIs) by up to 71% in adult hemodialysis patients. I knew immediately that this was what I needed.

What followed was a 10-month journey. My dialysis center had never heard of DefenCath. I reached out to senior staff, the manufacturer, and anyone who could help, and kept pushing until I finally received it in August 2025.

What started as a personal pursuit became something bigger when I realized I couldn't be the only one fighting this battle. Around 360 people a day begin some form of treatment for kidney failure in the United States. How many of them even know DefenCath exists?

DefenCath is currently covered under TDAPA, which reimburses providers each time it is dispensed, But that coverage ends in June. Beginning in July, it moves into the bundled payment system, a flat fee intended to cover all patients who could benefit. If that reimbursement rate isn't adequate, providers may be financially disincentivized from using it, even for high-risk catheter patients like me.

Innovation means nothing if patients can't access the innovations. That's why I support legislation like the Kidney Care Access Protection Act, which would create sustainable payment pathways for groundbreaking treatments and ensure that breakthroughs actually reach the patients in dialysis chairs. One in three Americans is at risk for kidney disease. It's a silent killer that rarely gets the attention it deserves. It's time for that to change.

I'm still waiting for my next transplant. But most importantly, I'm still fighting, not just for myself, but for every patient who deserves better access, faster innovation, and a healthcare system that keeps up with what science offers.

Hope, Innovation, and Life Reimagined

By Albert Bailey Brisbane III, DPC Patient Ambassador

I was a teenager when I first heard the word dialysis.

In 1981, my father suddenly became critically ill while at work and was rushed to the hospital, where he passed away two weeks later. I remember being told that he refused dialysis. I didn't know what dialysis was, only that my hero was gone forever.

Years later, I heard that word again — dialysis. This time, it was my mother.

Her experience came suddenly, and she began emergency dialysis in the hospital. In that moment, my sister and I didn't think about treatment. We thought about death because that had been our only reference point. We pleaded with our mother to fight and not to lose hope.

We learned all we could about ESRD to best support our mother. We needed her to live, not just survive.

When my father became ill in 1981, treatment options were limited. Dialysis was often performed in hospitals, as there were few independent centers. Conversations about kidney disease were rare, and travel (or anything resembling normal life) was often out of reach.

By the time my mother began dialysis years later, progress had begun, but awareness and access were still evolving.

Today, the landscape has changed dramatically because of innovation. Dialysis centers are more widely available, home therapies such as peritoneal dialysis and home hemodialysis offer greater flexibility, and advancements in medications, vascular access, and technology have improved both lifespan and quality of life. Many

patients can now work, travel, and live with far less disruption.

When I heard the word dialysis a third time, it was about me.

In my early 50s, I began experiencing health challenges, and after a year of testing, I was told to prepare for dialysis. I had always lived a healthy, active life, so it was surprising to learn that I had focal segmental glomerulosclerosis (FSGS), a rare disease affecting about 7 out of 1 million people. Because early symptoms are often mild or nonexistent, it went undetected for years.

My mind immediately went back to my father. I began to wonder if it was my fate to die young the way he had at 44.

By this time, my mother was thriving on dialysis. She encouraged me to have a fistula placed so that when the time came, I would be better prepared for treatment. Her wisdom and lived experience gave me confidence.

I watched her go from not knowing what dialysis meant to becoming a powerful advocate and Patient Ambassador with Dialysis Patient Citizens (DPC). She educated herself, advocated for her own care, and then for others new to dialysis — showing me what was possible — and encouraging me to get on the transplant list.

I was successfully transplanted within four years by a team at Mount Sinai Hospital in New York City, following a younger cousin who had been transplanted by the same team a few years earlier. We both remain under their care, and advances in technology and medicine have allowed for life-saving adjustments in real time; extending the life of our kidneys and, with it, our future.

I've traveled to Paris for the 2024 Olympic Games with my cousin, Olympic legend Bob Beamon, an experience that once would have felt out of reach.

I reclaimed my life as a professional musician and began traveling again. Bob and I, both professional musicians, performed in concert with Ibrahim Malouf at the world-renowned Olympia Theatre in Paris; another reflection of what is possible today.

I carry my father's story and my mother's example, both shaping how I choose to live. They taught me that ESRD is not the end of life, just the end of kidney function.

At the time of my mother's diagnosis, I began to understand something I couldn't have understood as a teenager.

My father didn't give up. As much as he didn't want to leave us, he advocated for himself by saying no at a time when dialysis was not associated with possibility. He made the best decision he could with the information he had in such little time.

At that time, outcomes looked very different. In the early 1980s, many patients on dialysis lived only a few years, and survival rates were far lower than they are today. Through the 1990s, advances began to improve longevity, but uncertainty remained. Today, many patients live five to ten years or longer, some for decades, with access to better treatment, technology, and support.

Understanding that reality helped me see my father's decision with greater clarity and compassion.

Today, I continue my mother's path as a Patient Ambassador with DPC, while also mentoring patients at my church and former dialysis center — helping others navigate a journey that once felt uncertain for us.

I am the hope my father lost and the hope my mother gave.

Hope and innovation are not just about treatment, they are about access.Access to information, to options, and to the ability to make informed decisions.

Because of my mother, because of innovation and access to information, I am here.

Living.

After seven years on dialysis and three years post-transplant, I'm not just surviving. I'm living a life that once didn't seem possible.

One week of typical phosphate binders (left) vs. one week of Unicycive's new phosphate binders (right) pending approval later this year

Dialysis patients are missing out on new therapies due to Medicare's ESRD payment structure

By Quiana Bishop,
DPC Board President

While dialysis treatments sustain life for people with kidney failure, they cannot replace all of the many functions of a healthy kidney. Patients rely on medications to address certain symptoms. As of January 1, 2025, all of these medications are included in the ESRD prospective payment system bundle and dialysis facilities are given the responsibility of dispensing them. This arrangement saves money for Medicare, but it does so by creating a profile for an "average patient" and discouraging expenditures on anyone else. As we know, there's no such thing as an "average" patient, with the result that innovative treatments developed for those who need extra, are not getting to those patients who need them.

One of the conditions addressed by medications is phosphorus. Phosphorus is absorbed in the small intestines and stored in the bones. Healthy kidneys get rid of the extra amounts not needed in the body. Because unhealthy kidneys are no longer able to remove phosphorus from the blood and get rid of the excess in urine, high levels of phosphorus (hyperphosphatemia) is a problem for people with end stage renal disease.

This can cause bone and heart problems that lead to hospital stays and in some cases, death; calcification or hardening of tissues when phosphorus and calcium form deposits in the heart, arteries, joints, skin, or lungs that can be painful and lead to serious health problems; and puritis (itching).

Until recently, the only treatment for high phosphorus was phosphate binders, large

pills that must be taken in large quantities. Because I had a gastric sleeve done several years ago, the phosphorus binders expand in my now much smaller stomach. Then I can't eat. If I can't eat, I miss out on all the other nutrients and vitamins you gain from eating. So, I have battled with my phosphorus. I have tried all types of binders with not very good results. And all these years of uncontrolled phosphorus has caused calcium deposits throughout my veins, throughout my entire body, which complicates my eligibility for transplantation.

An innovative treatment for phosphorus is Xphosah, a phosphate blocker. I was prescribed and received this drug from my Medicare Part D plan until it was rolled into the ESRD bundle. It has worked well for me and I feel like if there was access to these new medicine years ago, I would be on the transplant list or, better yet, would have a kidney by now. But because of an impasse between the manufacturer, Ardelyx, and Medicare over the terms, Medicare no longer covers this drug. I am fortunate that Ardelyx is providing me with the drug for free for the time being, but this is not a sustainable solution for patients.

Ardelyx's dispute with Medicare centers on whether its Transitional Drug Add-On Payment Adjustment (TDAPA) for new medications is inadequate. DPC thinks it's not, and that new therapies need to be paid for separately in a sustainable manner.

There's no guarantee that payment bundling will be safe and efficient for patients. First of all, it can't be safe if there is significant variation in patients' needs. The bundle intentionally incentivizes providers to administer less treatment. This can be helpful if excessive treatment is wasteful or dangerous. But when some patients require more than the standard treatment, providers may default to the usual care to avoid the extra expense.

For years, kidney care relied on old and inexpensive drugs to address various conditions. It did not matter that not every dialysis patient has ESRD-related puritis (itching) when the standard treatment was a Benadryl tablet that costs a penny. But the introduction of Korsuva, a drug to treat ESRD-related puritis, changed that. The requirement that this drug go in the bundle has resulted in a de facto embargo of the medication. Empirical research has found a prevalence of moderate to severe puritis among dialysis patients of 33 percent, but Korsuva has been dispensed to fewer than one percent of patients. CMS baked the artificially low take-up during the TDAPA period into the cake, adding a tiny amount to the bundle for the drug and locking in a depressed rate of utilization in perpetuity.

In my case, while most patients respond well to phosphate binders, I and many others do not. When the payment is fixed and Medicare treats me like the "average" patient, I become an expensive patient in the eye of providers. The experience under TDAPA is that we exceptional patients are not getting the new drugs.

Bundling also assumes that there are consensus protocols followed by clinicians when it includes dollars for a particular intervention. That is not always how things work, especially when an intervention is new. In the kidney care world, the management of dialysis organizations determines protocols and formularies for each of their clinics. If fewer than all providers implement a new drug in their facilities, and CMS averages the take-up across all patients, the new component of the payment will only partially reimburse the treatment for the adopting clinics, and leave a windfall for clinics sticking to the status quo. This scenario appears to be in play for two current TDAPA drugs that are not being adopted profession-wide.

Finally, bundling assumes that savings from new protocols benefit the provider. The bundled payment for hospitals incentivizes them to manage stays efficiently, and to drive a hard bargain with their suppliers. If they succeed, they keep the difference between the bundled price and their costs. Patients are protected by the right to a real-time appeal of discharges.

But the gains from new protocols in the ESRD bundle don't go to providers. DefenCath is a catheter lock solution whose costs are borne by dialysis organizations while the benefits—reduced infections and hospitalizations—accrue mostly to patients and the Medicare Trust Fund. Vafseo, an oral HIF-PHI to treat anemia in dialysis patients, could reduce transfusions for patients who don't respond to ESAs, but that too is a benefit to patients and to Medicare, not to the bundle gatekeeper. Meanwhile, patients can't appeal a lack of access to a new therapy that their doctor hasn't prescribed and that they most likely don't even know about.

We now see drugmakers retreating from the development of dialysis drugs. Many millions of dollars were invested to improve kidney care, but manufacturers' negative experience under bundling means venture capital is unlikely to make such investments in the future.

Fortunately for patients, kidney care champions in Congress have introduced legislation to remedy this problem. H.R. 6214, the Kidney Care Access Protection Act (KCAPA), would extend additional payments for innovative therapies. Visit **https://kidneyaction.org/support-s-2730-hr-6214-the-kidney-care-access-protection-act/** or scan the QR code to contact your representatives in Washington and ask them to co-sponsor this important bill.

Innovation, Hope, and the Gift of a Second Chance

A Gift That Rewrites a Life

By C. Andre' Daniels,
DPC Patient Ambassador

Hope is not passive.
It is not a soft sentiment or wishful thinking.

For patients living with End-Stage Renal Disease, hope is often an act of discipline. It is the decision to keep going through the fatigue, the uncertainty, the appointments, the waiting, and the fear. It is the choice to believe that even in the face of illness--innovation, faith, and human generosity can come together to rewrite a life.

I know this because I have lived it. When I woke up after my kidney transplant, I knew immediately that my life had changed. What I did not yet fully understand was how profoundly that gift would reshape my days, my priorities, and my purpose. I had been given more than just a successful surgery. I had been given a second chance, and with it came a new responsibility: to protect that gift, to honor it, and to use my experience to encourage others who are still fighting their way forward.

In the weeks after transplant, my life became defined by vigilance and gratitude in equal measure. Weekly labs, medication schedules, follow-up appointments, and careful monitoring became part of my daily rhythm. My immune system, now deliberately suppressed to protect the transplanted kidney, required constant awareness. Masks, disinfecting surfaces, avoiding crowded places, and paying attention to every cough, fever, or change in how I felt became routine.

Simple things took on new significance. Sunlight meant sunscreen and hats. Entering a room meant considering distance, airflow, and exposure. I had to listen to my body in ways I never had before—tracking blood pressure, glucose, weight, cholesterol, and viral markers, while learning to live with side effects like tremors and fatigue.

It was humbling.
It was exhausting.
And yet, it was miraculous.
Because behind every blood draw, every pill organizer, and, every clinic visit, was one astonishing truth: I was alive because someone chose to give.

Where Innovation Meets Humanity

When we talk about innovation in kidney care, many people think first about machines, medications, and medical breakthroughs. And rightly so. Innovation matters. Advances in transplant medicine, immunosuppressive therapies, clinical monitoring, and coordinated care make survival and long-term graft success possible. The transplant itself is a miracle of science, skill, and precision.

But innovation is not only found in technology. It is also found in systems of care, in patient education, in better advocacy, in increased awareness around living donation, and in the courage of people willing to say yes to helping another human being live.

My transplant journey taught me that innovation and hope are deeply connected. One gives us tools. The other gives us the reason to keep using them.

The doctors, nurses, coordinators, social workers, and specialists who guide transplant patients are doing far more than treating organs. They are helping restore futures. They are walking patients through what often feels like a second birth—one filled with equal parts wonder, caution, and adjustment. Their expertise steadies us. Their vigilance protects us. Their reassurance carries us through some of our most vulnerable moments.

And still, for all the science involved, the heart of this journey remains profoundly human.

Honoring a Living Donor

I named my donor **Nova Journey**—a symbol of new beginnings, courage, and extraordinary generosity.

Living donation is not theoretical to me. It is not a talking point, a brochure, or a distant concept. It is the reason I get to see another sunrise. It is the reason my family can exhale with relief. It is the reason tomorrow is no longer something I merely hoped for, but something I am blessed to inhabit.

In moments of uncertainty—waiting for lab results, confronting infections while immunocompromised, or enduring unexpected stays in the ICU—I reminded myself that this kidney was more than an organ. It was trust. It was sacrifice. It was love expressed through action.

Every day I carry that gift with reverence.

That is why living donors deserve not only our thanks, but our public honor. They are part of one of the most powerful forms of innovation in healthcare: the willingness of one person to step forward so another person can keep living.

Learning to Live Again

One of the truths people do not always discuss enough is that transplant recovery is not linear.

There were setbacks. There were infections. There were frightening moments when lab numbers shifted, my heart raced, and I found myself back in emergency rooms and intensive care units. There were days when fear entered quietly and nights when gratitude kept me awake.

But alongside those moments, something else grew stronger: resolve.

I learned that transplant life is not about returning to the person you were before illness. It is about becoming someone new. Someone more attentive. More grateful. More aware of how fragile and extraordinary life truly is.

Between appointments, I practiced patience.
Between lab reports, I practiced hope.
Between moments of fear, I practiced gratitude.
That practice matters.

Remaining hopeful does not mean denying reality. It means facing reality honestly while refusing to surrender your spirit to it. It means understanding that the road may be hard and still believing it is worth walking. It means allowing gratitude to coexist with vigilance, and faith to coexist with uncertainty.

For kidney patients and transplant recipients alike, hope often lives in the ordinary routines of survival. It lives in taking the medicine. Showing up to the clinic. Getting on the machine. Following through. Asking questions. Staying informed. Trusting God. Trusting the process. Trusting that your story is still being written.

From Survivor to Advocate

As a civic leader and longtime community servant, I have always believed that our lives carry obligations beyond ourselves. My transplant deepened that conviction.

I realized quickly that my story was not meant to remain private. It was meant to be shared.

Shared with families wondering whether living donation is safe.
Shared with patients still waiting and wondering if their call will ever come.
Shared with communities that have never seriously considered organ donation.
Shared with people who need to know that second chances are real.

Advocacy became part of my healing. Whether speaking publicly, participating in kidney walks, supporting awareness efforts, or encouraging people to have meaningful conversations about organ donation, I now see every opportunity as a chance to honor the person who helped save my life—and the broader transplant community that made that miracle possible.

If my voice can shorten someone else's wait, then I must use it.
If my experience can calm another family's fear, then I must share it.
If my gratitude can inspire one more person to consider donation, then this gift keeps multiplying.
That is how hope becomes action.

A Message for Patients Still Fighting

For those still on dialysis, I want to say this plainly: I know the fight is real.

I know what it means to live by numbers, schedules, treatments, and uncertainty. I know the emotional toll, the physical fatigue, and the quiet battles that many patients fight without ever fully putting them into words. I know what it means to hold on when the days are long and the future feels distant.

But I also know this: your life still holds possibility.

Innovation in kidney care continues to evolve. Advocacy continues to matter. More people are learning about living donation. More patients are sharing their truths. More families are becoming part of the conversation. There is reason to remain hopeful—not because the journey is easy, but because progress is real and purpose can still be found even in the struggle.

Never underestimate the power of your testimony. Your survival is not small. Your endurance is not invisible. Your fight has meaning.

Gratitude That Endures

Transplant life is lifelong. The medications will remain. The labs will continue. The precautions will stay part of my daily rhythm.

But so will the awe.
So will the reverence.
So will the commitment to live intentionally.

I wake up each day knowing that someone I may never fully repay gave me the chance to keep writing my story. The best way I know to honor that gift is to protect it, to share it, and to serve others with renewed purpose.

I am here because generosity exists in this world.
That truth should move all of us—patients, caregivers, clinicians, policymakers, donors, and advocates alike. Because when we talk about innovation in kidney care, we must never lose sight of the fact that the greatest breakthroughs are not only scientific. They are also human. They are found in compassion, courage, and the willingness to act on behalf of someone else's future.

A Message to Future Donors and Supporters

To those considering living donation,
to families wrestling with fear and hope,
to supporters who make transplant programs possible,
and to advocates who continue to spread awareness:
Know this—
you are not simply saving organs.
You are restoring futures.
You are keeping families whole.
You are giving time, the most precious gift of all.
Because of you, I am still here.
Because of you, my story continues.
Because of you, life has been given again.

Kidney Innovators Highlight New Therapies

Medicare Challenges at Congressional Hearing

By Jackson Williams, DPC
Vice President of Public Policy

On March 18, 2026, the House Ways and Means Subcommittee on Health held a hearing titled "Improving Kidney Health Through Better Prevention and Innovative Treatment". This hearing allowed patients, providers, and other stakeholders to highlight the struggles many kidney patients face and the barriers that prevent them from accessing better, innovative treatment.

This was exciting for kidney care advocates, as challenges have mounted since Congress last addressed kidney health in 2008. Better still, the questions from Members of Congress demonstrated that committee leaders understand those challenges and potential solutions. They are knowledgeable about these issues in large part because patients have shared their experiences and insights.

These excerpts from statements to the committee submitted by kidney health innovators summarize some of the exciting developments in improving dialysis care. But they also show how Medicare's payment policies discourage adoption of these new therapies.

John Butler
Akebia Therapeutics

Although innovation in many areas of science has been transformative, there has been little innovation in dialysis, prompting nephrologists to call dialysis a profound "innovation desert."

The Centers for Medicare & Medicaid Services (CMS) tried to address the statutory deficiencies of MIPPA by creating a Transitional Drug Add-on Payment Adjustment (TDAPA) in 2020 to provide payment for innovative drugs on top of the base rate, but only for two years. While well intended, the limited duration of the TDAPA period creates obstacles for the adoption of innovative therapies in dialysis settings. Two years is not sufficient time for dialysis providers to assess the value of a new treatment option for their patients, conduct pilots in their facilities, evaluate real-world impact, establish new protocols, engage in contracts, and educate clinical staff. In addition, physicians are generally unwilling to prescribe a new drug if they are concerned that patients will lose access once the TDAPA period ends, due to limitations in the dialysis facility's prescribing list or formulary.

Experience to Date

There have been only four innovative dialysis drugs approved by the Food and Drug Administration (FDA) and granted TDAPA by CMS since its inception. The first two drugs reached less than 1% of dialysis patients during their TDAPA periods, despite significant unmet need in their therapeutic areas.

Korsuva (difelikefalin) is the first and only FDA-approved therapy for CKDassociated pruritus, a condition that affects approximately 35 percent of ESRD patients. Korsuva received breakthrough status from the FDA, which is awarded to investigational products that demonstrate significant improvement over existing therapies for serious or life-threatening conditions. The condition is characterized by intense and relentless itching, skin lacerations, scarring and infections, all of which diminish patient quality of life. The cost to the Medicare system of treating infections and hospitalizations related to pruritus can be significant.

During its TDAPA period, nephrologists were unwilling to prescribe Korsuva, knowing they would have to take patients off the product after its two-year TDAPA, which ended on March 31, 2024. Even physicians who served as principal investigators in the clinical trials and had directly observed the drug's efficacy, felt it would be "unethical" to provide relief for patients during the drug's TDAPA period, if forced to withdraw treatment due to lack of payment in the post-TDAPA period.

Now in that post-TDAPA period, dialysis organizations are unwilling to make Korsuva available because of the inadequate Medicare reimbursement under CMS' flawed post-TDAPA policy. CMS pays $0.11 per dialysis session for a product that costs facilities about $27 per session. This means a typical dialysis facility would have to receive that $0.11 from 250 patients to have the resources to support a single patient with Korsuva, when an average facility census is 60-80 patients. Although the product continues to be available for purchase under an agreement with another company, Cara Therapeutics, the developer of Korsuva, ceased operating as an independent company.

Jesduvroq (daprodustat), the second TDAPA drug, was a first-in-class drug to treat anemia in dialysis patients. GSK, the developer of Jesduvroq, removed the drug from the U.S. market at the end of 2024 – before even finishing the product's

TDAPA period, likely recognizing that the bundle's reimbursement is inadequate to support continued patient access. GSK has abandoned further dialysis research.

The failure of the first two TDAPA drugs to reach the patients for whom they were developed demonstrates that TDAPA has not achieved its intent. Without changes, access to the two current TDAPA drugs could be compromised as well. Not only could patients lose potential clinical benefits, but the Medicare system could lose significant savings from reduced hospitalizations and other downstream costs.

VAFSEO® (vadadustat), Akebia's product, is a hypoxia-inducible factor prolyl hydroxylase (HIF PH) inhibitor indicated for the treatment of anemia due to chronic kidney disease in adults who have been receiving dialysis for at least three months. The unique mechanism of action (MOA) was built on Nobel Prize-winning science in 2019. This novel drug provides an important alternative to pre-existing erythropoiesis-stimulating agents (ESAs). As an oral anemia treatment, it provides a significant practical advantage for patients on home dialysis making it important to the goal of expanding home modalities, as well as offering simple titration and fewer dose modifications for patients choosing any dialysis modality.

The clinical evidence and early data generated since launch of VAFSEO shows significant potential value for patients with ESRD and the Medicare program. A posthoc analysis of the pivotal Phase 3 INNO2VATE trial in patients undergoing dialysis showed a statistically significant reduction in the composite endpoint risk of death and hospitalization with VAFSEO compared to darbepoetin alfa (an ESA). In addition, a cost comparison analysis of the data showed VAFSEO has significant impact on the cost of hospitalization versus darbepoetin – about an 8% reduction in hospitalization rate, a 16% reduction in hospital days, and a 15% reduction in Medicare hospitalization costs. Nearly $2 billion in annual savings to Medicare could be achieved if all eligible beneficiaries received VAFSEO.

Legislative Solution

Given the urgency of dialysis patients losing access to new innovative products in real time due to the lack of sustained funding, Akebia urges the Subcommittee to act on important legislation that was introduced by two of its members, Congresswomen Carol Miller (R-WV) and Terri Sewell (D-AL). As long-term champions for kidney patients, their legislation, H.R. 6214, the Kidney Care Access Protection Act (KCAPA), would take concrete steps to address the lack of access to innovation.

Joseph Todisco
CorMedix Therapeutics

Patients with end-stage renal disease face a heightened risk of serious, often life-threatening complications. The hemodialysis access required to sustain their lives often exposes them to dangerous bloodstream infections that often times are fatal.

Approximately 25% of ESRD patients who receive hemodialysis use a central venous catheter (CVC) for vascular access. 80% of new ESRD patients begin hemodialysis via CVC. Catheter-related blood stream infections (CRBSIs), are among the most common and life-threatening complications of hemodialysis delivered through a CVC, and DefenCath®, our unique therapy, is the only FDA-approved drug product indicated to reduce this risk in adult patients with kidney failure.

CRBSIs happen fast, usually within the first 90 days after hemodialysis patient has a catheter inserted. CRBSIs happen often, as approximately one third of catheterized ESRD patients will contract a CRBSI. CRBSIs kill at an alarming rate, as approximately 25% of them are fatal, making these preventable infections a leading cause of morbidity and mortality in the ESRD population. Moreover, they are a major driver of excess and avoidable Medicare spending. Recently published data indicate that CMS alone spends more than $2.3 billion per year on treatments and hospitalizations related to CRBSIs in the ESRD population.

DefenCath's pivotal phase III study, LOCK-IT-100, demonstrated a 71% reduction in risk associated with CRBSIs in adult patients. DefenCath has been commercially available for approximately 21 months, and the realworld evidence confirms results consistent with those observed in the clinical trial. In a large-scale patient analysis conducted with US Renal Care, the third largest dialysis provider in the U.S., DefenCath replicated a greater than 70% reduction in CRBSIs and was associated with a corresponding reduction in CRBSI related hospitalizations. Additional data from another customer, a mid-sized dialysis operator, showed a 97% reduction in CRBSIs following a broad implementation of DefenCath across catheterized ESRD patients. Together, these outcomes represent meaningful improvements for patients and suggest substantial opportunities to reduce avoidable Medicare spending.

The success of DefenCath in improving overall kidney health, the improvement in patient outcomes, and potential reduced Medicare spending, is in jeopardy with the pending expiration of temporary direct reimbursement under the current ESRD Prospective Payment System (PPS) on June 30th. Innovative drugs in ESRD currently receive only two years of separate reimbursement under CMS's Transitional Drug Add-On Payment Adjustment (TDAPA), followed by only three years of a post-TDAPA bundle adjustment.

Preventing CRBSIs saves lives and avoids costly and disruptive hospital admissions. It allows patients to remain in routine outpatient dialysis - the highest-quality and most costeffective care setting - while preserving overall health and transplant eligibility. Even a single CRBSI can disqualify a patient from kidney transplantation, the preferred long-term therapy for ESRD and a priority under the Administration's Make America Healthy Again (MAHA) initiative. For Medicare, which covers over 80% of ESRD patients, widespread adoption could generate billions in savings by avoiding hospitalizations and related costs.

ESRD patients have historically had access to the fewest innovative therapies of any major disease population, reflecting the structure of the ESRD PPS and the short-term nature of TDAPA. TDAPA was intended to encourage innovation through temporary separate reimbursement for new drugs, but the structure has proven to unintentionally undermine patient access. Two years is insufficient for providers to pilot programs, implement protocols, train staff, negotiate contracts, and collect robust real-world data to determine if broader use is warranted. The temporary payment followed by the impending "reimbursement cliff" also discourages dialysis providers from initiating novel therapies. As a result, the current framework limits patient access to innovation and constrains the personalization of care.

Challenges, Opportunities, and Innovation in

End Stage Kidney Disease and Transplantation

By Dr. Velma Scantlebury, MD, FACS, GCM, DPC Education Center Health Care Consultant

Over 90,000 patients sit on dialysis awaiting kidney transplantation, and thousands more are on some form of dialysis modality, with the hope of maintaining life without a kidney transplant. From chronic kidney disease (CKD) to end stage kidney disease (ESKD) there are significant challenges for both patients and healthcare providers, including delays in the onset of dialysis, complications associated with dialysis, limited access to donor organs and the need for lifelong immunosuppression following transplantation. Additionally, socioeconomic disparities and geographic barriers often impact the quality and availability of care.

A. Innovations in CKD

1. GLP-1 Receptor Agonists: Improving Kidney and Cardiovascular Health

Diabetes remains the most common cause of ESRD and is a major contributor to cardiovascular and metabolic disorders. There is growing evidence of the use of glucagon-like peptide (GLP-1) receptor agonists can improve overall kidney function by improving glucose control as well as cardiovascular risk reduction (1). It is important that GLP-1 receptor agonists be recommended and closely monitored by healthcare professionals, taking into account each patient's individual risk factors and other health conditions. Proper medical supervision ensures optimal outcomes and minimizes potential side effects or complications associated with these therapies.

2. SGLT2 Inhibitors: Kidney and Heart Protection

Another group of drugs, referred to as sodium-glucose co-transporter 2 (SGLT2) inhibitors can be used to treat patients with CKD. These SGLT2 inhibitors were originally developed for the treatment of type 2 diabetes (T2D). Over time, additional research demonstrated that these medications not only help manage blood sugar levels, but also provide substantial benefits for kidney and heart health. Patients who are not diabetic have experienced improvements in overall kidney function when using SGLT2 inhibitors.

B. Managing Complications of CKD

For many patients with CKD as well as ESRD not yet on dialysis, there are many abnormalities that arise that cannot be easily treated by medication that require good kidney function to be metabolized. Currently there is hope for some of these conditions:

1. Metabolic acidosis – a condition where the body accumulates too much acid. A new drug is being studied in adults with CKD that will eliminate excess acid in the body and increase bicarbonate levels. This is in Phase 3 clinical trial currently.
2. Anemia – correcting anemia of kidney disease can be challenging. A recent study has shown that vadadustat (Vafseo), an oral medication taken once daily, is just as effective as current injectable medications for managing anemia in dialysis patients.
3. High phosphorus levels – this is a significant issue for many dialysis patients. While the standard medications are phosphorus binders, the FDA approved Xphozah (tenopanor) in 2023. Oxylanthanum Carbonate (OLC) is a current medication under review by the FDA. It uses nanoparticle technology to improve phosphorus binding potency and decrease the number of pills needed.

C. Development in Innovative Kidney Preservation

Advances in organ preservation techniques, the development of artificial kidneys, and improvements in immunosuppressive therapies offer hope for better outcomes and increased organ availability. With the limiting factor being the availability of organs, there are many innovations aimed at not only improving the viability of available organs, but alternative options for human donor organ replacement:

1. Machine Perfusion

- The **Room Temperature Machine Perfusion (RTMP)** device could make more kidneys available for transplant. Many donated kidneys are not used today because they can be damaged during cold storage. This RTMP device keeps kidneys healthy longer

by perfusing the organs at room temperature, allowing doctors to test how well they work before kidney implantation. The FDA recently gave the device breakthrough status, which speeds up review of technologies that could improve patient care.

- New technologies like the **Kidney Pod** and **NoMo™ Kidney Pump** keep donor kidneys at body temperature with oxygen and nutrients during transport. This can "resuscitate" kidneys that were previously considered too poor in quality, significantly reducing the number of discarded organs.

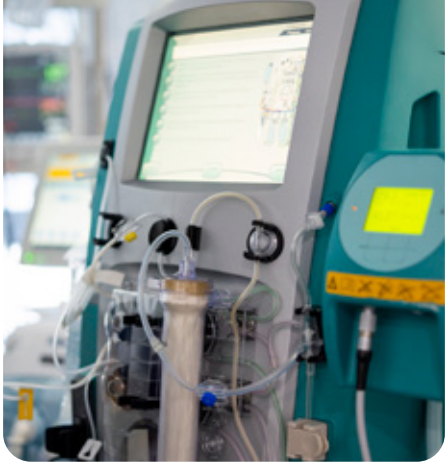
2. Artificial kidneys

Research into the implantable/wearable "bioartificial" kidney device has been in development for over 12 years. Engineered like a small dialysis/tubule system, it held the promise of providing patients with kidney failure another option other than machine dialysis and/or waiting for a kidney transplant. These **Artificial kidneys**, when utilizing a patient's own cells, are designed to work like real kidneys without the risk of rejection.

Artificial kidneys are being developed in two main ways. First are wearable or implantable bioartificial kidney devices, which are engineered much like a miniaturized dialysis system: blood flows across a biocompatible membrane with carefully sized pores that allow water and small waste molecules to pass while keeping blood cells and proteins in the bloodstream. Some designs add a second "tubule" component by utilizing human kidney cells that are programmed to replicate on a scaffold so they can help regulate electrolytes and fluid balance, making the device behave more like a real kidney.

The second approach is tissue engineering (regenerative medicine), in which scientists attempt to grow kidney tissue using stem cells or a donor-organ scaffold that has had its cells removed and then is "re-seeded" with new cells. A key challenge for lab-grown kidneys is building enough tiny blood vessels (vascularization) and achieving full, durable kidney function at human scale.

Wearable versions require a power source such as a pump/battery. Implantable versions are powered by the patient's blood pressure to move blood flow through the system. Researchers are optimistic that such devices may be approved by 2030.



3. 3D kidneys

Mayo Clinic researchers use 3D bioprinters to create living models of skin, cartilage, and organ tissue using medical imaging and patient-specific cells. These tissue models help scientists study disease, test treatments, and develop future transplant solutions. While still in development, this technology offers hope for patients facing organ failure or donor shortages.

D. Expanding the Organ Supply

Innovative approaches such as xenotransplantation, regenerative medicine, and precision medicine are being explored to address the shortage of donor organs and improve transplantation success rates. Collaborative efforts between researchers, clinicians, and policymakers are crucial to drive progress in this field, ensuring that patients with ESKD receive optimal care and support.

1. **Xenotransplantation:** This is the process of implanting cells or organs from a non-human source into humans. 2025 marked a massive leap with the first clinical trials transplanting **modified pig kidneys** into living human patients. This is made possible by genetically modifying the donating animal by removing certain genes that are responsible for the genetic incompatibility. This reduces the rejection rate, but does not eliminate it. This technology aims to eliminate the transplant waiting list entirely by providing a sustainable source of organs. While there are potential benefits, the process of xenotransplantation exposes the recipient to infections from cross-species organisms that may become a concern.
2. **Enzyme Technology for Universal Organs:** Since blood type "O" is the only blood type that has no "A" or "B" antibodies, a new technology has allowed for the removal of surface molecules from the red blood cells, thus converting A or B blood types into O blood type. In 2025, researchers have successfully used these specific enzymes to "convert" a donor kidney's blood type from A to O, allowing for implantation into a brain-dead recipient (with family consent). By removing the potential for antibody development by incompatible kidneys, this opens the pathway for providing more universal donor organs and reducing matching barriers that currently disqualify many pairs of donor-recipient combinations,

Conclusion

End stage kidney disease remains a high-burden condition driven by progressive CKD, limited organ availability, and the long-term challenges of dialysis and transplantation. However, the landscape is rapidly changing: therapies such as GLP-1 receptor agonists and SGLT2 inhibitors are improving cardio-renal outcomes, newer options for complications like acidosis, anemia, and hyperphosphatemia are emerging, and transplant success may improve through better organ preservation technologies such as machine perfusion. At the same time, bioartificial kidneys, 3D tissue engineering, xenotransplantation, and enzyme-based "universal organ" strategies offer potential paths to expand the donor pool and reduce time on the waitlist. Advancing these innovations will require continued research, careful monitoring for safety and durability, and equitable access so that these advances benefit all patients with CKD and ESKD.

References

1. Pan, HC., Chen, JY., Chen, HY. et al. GLP-1 receptor agonists' impact on cardio-renal outcomes and mortality in T2D with acute kidney disease. Nat Commun 15, 5912 (2024). https://doi.org/10.1038/s41467-024-50199-y

2. POSTGRADUATE MEDICINE2025, VOL. 137, NO. 6, 450–457https://doi.org/10.1080/00325481.2025.2517531

3. Kidney Transplantation: Current Barriers and Evolving Policies - Avalere Health Advisory

4. Marking National Kidney Month with An Outlook in the 2026 Kidney Care Policy, Payment, and Treatment Landscape | Avalere Health Advisory

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 `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.*

Lemon Blueberry Surprise Muffins

Recipe provided by **Fanny Sung Whelan, MS, RDN, LDN.**

Prep Time: 10min
Cook Time: 10min
Total Time: 20min

Ingredients
Makes 9 servings
- 3 medium eggs
- 3 T. oil
- 1/4 c. heavy cream
- 1 1/4 c. vanilla whey protein powder
- 2 tsp. baking powder
- 5 packets Splenda
- 1/4 tsp. cinnamon
- 1 T. grated lemon rind
- 1/2 c. blueberries
- 3 oz. cream cheese, cut into 9 cubes

Instructions
Preheat oven to 375°F. Line 9 muffin tins with paper liners.
Combine the eggs, oil and cream. Stir to blend.
Add the whey powder, baking powder, Splenda, cinnamon and lemon rind. Stir until it combines. Do not over-stir or the muffins will be tough.
Fold in the blueberries and gently spoon 1/2 of the batter into the prepared muffin tins.
Place a cube of cream cheese in the center of each.
Fill the tins with the remaining batter, making certain that the batter goes completely and around the cubes of cream cheese.
Bake at 375°F for eight to ten minutes or until the tops are slightly browned.

Muffins Sorpresa de Limón y Arándanos Azules

Receta de **Fanny Sung Whelan, MS, RDN, LDN.**

Tiempo de preparación: 10 min
Tiempo de cocción: 10 min
Tiempo total: 20 min

Ingredientes:
Porciones: 9
- 3 huevos medianos
- 3 cucharadas aceite
- ¼ taza crema espesa para batir (heavy cream)
- 1 ¼ tazas de proteína en polvo de suero de leche (whey) con sabor vainilla
- 2 cucharaditas polvo para hornear
- 5 sobres de Splenda (o endulzante de tu preferencia)
- ¼ cucharadita canela
- 1 cucharada ralladura de limón
- ½ taza arándanos azules (blueberries)
- 3 oz queso crema, cortado en 9 cubos

Instrucciones:
Precalienta el horno a 375°F. Prepara un molde para 9 muffins con envolturas de papel.
Combina los huevos, el aceite y la crema espesa. Mezcla bien.
Agrega la proteína en polvo, el polvo para hornear, el endulzante, la canela y la ralladura de limón. Mezcla solo hasta integrar; no batas de más o los muffins quedarán duros.
Envuelve suavemente los arándanos en la mezcla.
Sirve la mitad de la mezcla en cada molde.
Coloca un cubo de queso crema en el centro de cada uno.
Añade el resto de la mezcla en cada molde, asegurándote de que el queso crema quede bien cubierto.
Hornea de 8 a 10 minutos o hasta que la parte superior esté ligeramente dorada.

Patient Stories are the "Secret Sauce"

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

Does advocacy have a "secret sauce" for success? Are there tactics and tools that an organization needs to consider as strategies are developed to get legislation passed? What does success look like? How does optimism and the cumulative impact of advocacy work impact positive outcomes?

Dialysis Patient Citizens (DPC) began a Medigap (Medicare Supplement) campaign in 2022 supporting legislation in the states to provide premium protected Medigap coverage to ESRD patients under-age 65. This campaign supports DPCs goals of improved financial security, increased patient choice and access to kidney transplantation.

Medigap is Medicare Supplement Insurance sold by private insurance companies that helps cover the "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 secondary coverage to help cover hospitalizations (Part A) and outpatient care (Part B). When Medigap plans were first introduced, Congress only guaranteed issue of these plans to traditional Medicare beneficiaries (those age 65 and older who are enrolled in Medicare Parts A and B) with consumer protections and did not extend this protection to disability and ESRD patients who obtain Medicare coverage prior to age 65. Without a federal mandate to extend coverage to all

DPC staff joined by coalition partners in Arizona in support of H.B. 2433

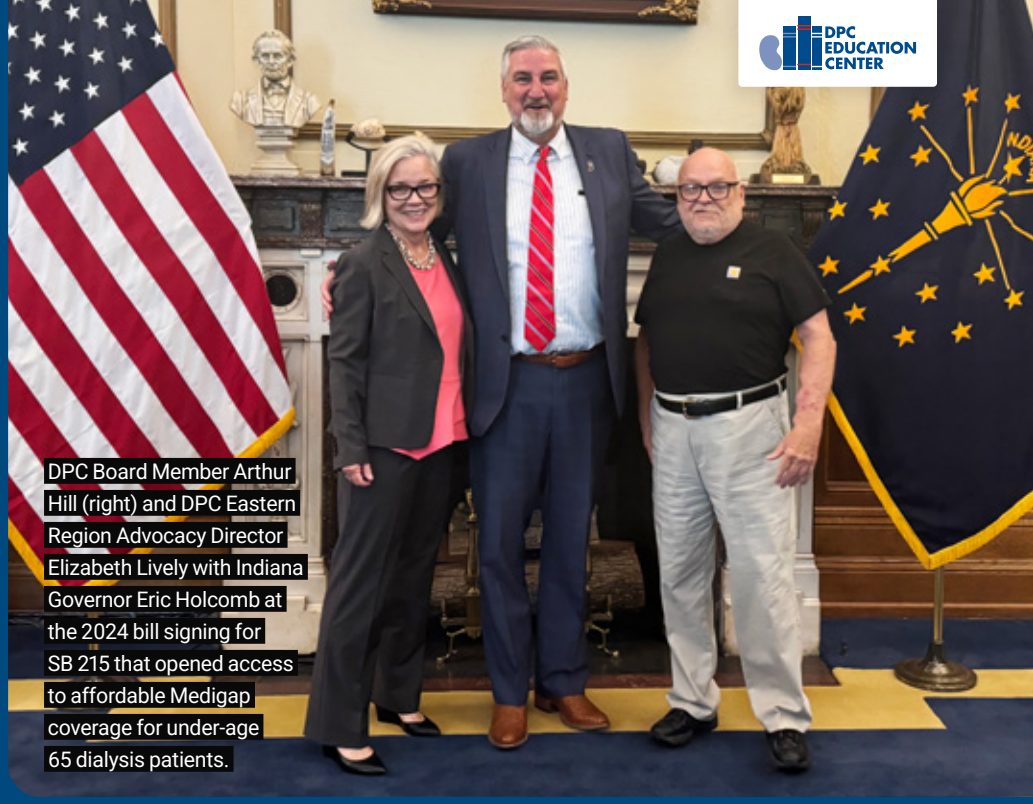
Medicare-eligible beneficiaries regardless of age, states are left to determine their own Medigap policy for ESRD patients under age 65.

Over the last four years, five states (Virginia, Kentucky, Indiana, Nevada, Texas) have passed Medigap premium protected legislation for End Stage Renal Disease (ESRD) patients under the age of 65, with one state (Rhode Island) passing a partial victory that may result in future positive amendments. Legislation is still active in three states (Ohio, Massachusetts, Michigan) with plans to continue our work next year in California, Arizona, Georgia. Nebraska, and Utah. This is what success looks like: actual wins combined with actively adjusting strategy in states that have positive momentum towards a future victory.

Of the five states that passed legislation, only Virginia passed legislation in the first year. Success in the other four states was cumulative – two and three years working the issue, building legislator support, collaborating with partner organizations, and engaging patient ambassadors to tell their stories directly to lawmakers. Our patient ambassador stories are a critical part of achieving success. Staying optimistic -- amid legislative sessions that are often short (30-45 days in many states) and filled with other issues competing with Medigap -- is so important.

DPC launched its Medigap campaign investing in development of a DPC Medigap Report Card housed on the **DPC website**, supported by state specific reports of CMS Medicare Claims data analyzed by Health Management Associates and the Berkeley Research Group. DPC used this data to push back on claims by the health plans that covering under-age 65 ESRD patients would make coverage unaffordable for seniors already enrolled in Medigap and that insurers would stop writing Medigap plans.

Trusted data from independent and respected sources is critically important. Without accurate data, our campaign would be futile. Legislators want to know the cost impact for their constituents. That is often their first question. The actuarial studies from Health Management Associates and the Berkeley Research Group presented premium impact data critically important



DPC Board Member Arthur Hill (right) and DPC Eastern Region Advocacy Director Elizabeth Lively with Indiana Governor Eric Holcomb at the 2024 bill signing for SB 215 that opened access to affordable Medigap coverage for under-age 65 dialysis patients.

to dispel the false claims from the health plans. The reports also provided DPC with estimated budgetary savings to state Medicaid programs to share with lawmakers. DPCs investment in these actuarial studies have resulted in the opportunity for thousands of under-age 65 ESRD patients to enroll in affordable Medigap coverage, keeping them off Medicaid and opening access to kidney transplantation. Having trusted data to share is the foundation of our Medigap campaign.

However, data is only one element of a successful legislative advocacy strategy. Personal stories from patients bring


Georgia State Senator Nikki Merritt, Chair of the Georgia Legislative Black Caucus, and DPC Board Member Christopher Richards at the Annual Heritage Gala.

actuarial data and the DPC Medigap Report Card to life. Advocacy work is about much more than just numbers. It's sharing how kidney failure impacts lives and how legislators can help patients. Telling patient stories is the "secret sauce" that adds momentum to any advocacy campaign. In each of the five states where DPC achieved legislative success, telling patient stories was the tactic that provided positive momentum. For example, in Virginia, the House bill sponsor had visited a dialysis center in his district, meeting patients and hearing their stories. This bill sponsor mentioned that experience every time he spoke about the importance of getting his bill passed. The result was unanimous votes in the Virginia House and Senate. An engaged bill sponsor motivated by patient stories is the "secret sauce" to our advocacy efforts.

DPC's patient ambassadors from states where legislation is active have multiple strategic ways to share their stories to help push our advocacy efforts forward, including letters to the editor, responding to action alerts, sharing their stories in person at committee hearings or submitting written testimony, attending meetings with legislators and DPC staff, or helping to facilitate a legislator visit to your dialysis center.

If you aren't already a DPC patient ambassador, click **here** or visit the DPC website at dialysispatients.org and click "Get Involved" to apply.

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