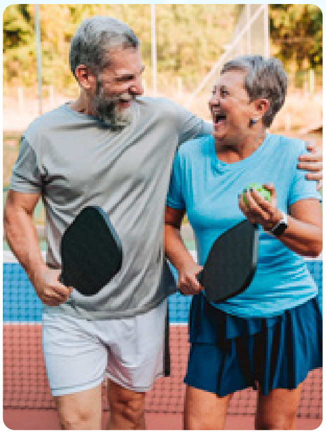
issue number 21

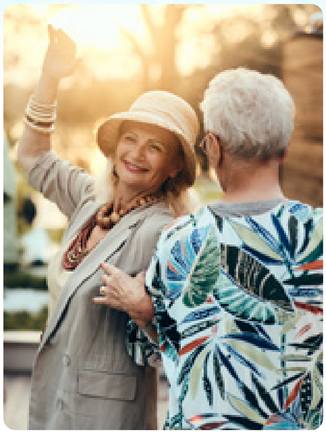
The Kidney Citizen

DPC EDUCATION CENTER

A publication of Dialysis Patient Citizens (DPC) Education Center



LIVING WELL with Kidney Disease



President's Message

As we celebrate the 21st issue of The Kidney Citizen, I'm reminded not just of how far we've come as an organization, but how far each of us has come in our own personal journey with kidney disease.

At Dialysis Patient Citizens, we've always believed that living well with kidney disease is possible, and that patients themselves are key to making that happen. Whether it's through advocacy, education, or simply sharing your story with others, every action taken by a patient makes a difference.

I see that difference in the faces of members who attended our most recent fly-in. Patients across the country came to Washington, D.C. to speak directly with lawmakers. Their voices are powerful reminders that kidney disease does not silence us. It motivates us. It connects us. And most importantly, it empowers us to shape the future for kidney care.

We're all at different stages of our journey. Some of us are newly diagnosed. Others have been navigating this path for over a decade. Kidney disease is complicated and often unpredictable, but one thing is clear: we are not alone.

This year, we continue to advocate for policies that support patient choice and access to care, including the Restore Protections for Dialysis Patients Act to restore access to critical health insurance coverage for patients who choose it.

But our greatest strength isn't just in the policies we pursue, it's in the community we've built together. A community of patients who support one another, speak out, and prove every day that living well is not only possible, but powerful.

Thank you for being part of this movement, and for inspiring others through your strength, resilience, and hope. Thank you for standing with us, and for showing the world what it looks like to live well with kidney disease. Remember to let your voices be heard. Your greatest power is your advocacy and being a part of this community!

Sincerely,

Merida Bourjolly

Merida Bourjolly,
President of DPC Education Center Board of Directors

CEO's Message

Since Dialysis Patient Citizens (DPC) was founded over two decades ago, our mission has been clear: to give dialysis patients a voice in the decisions that shape their care and lives. We've grown into the nation' largest patient-led dialysis organization, advocating for more than half a million Americans living with kidney failure, but at our core, we remain a community that uplifts one another.

This issue's theme, Living Well with Kidney Disease, resonates deeply with me. I was first diagnosed with kidney disease 14 years ago, shortly after joining DPC. Since then, my diagnosis has evolved, first through a biopsy, and later with newly available DNA testing. Like many of you, my journey hasn't been a straight line. That's why we believe so strongly in supporting every patient, no matter where they are on their path.

What we've learned from our members is this: living well with kidney disease is not just possible, it's powerful. Whether it's learning to manage treatments, advocating for better policies, or finding a community that understands, patients play an active role in their own well-being. And when patients get involved with DPC, they help shape a better future for everyone.

You'll see that spirit throughout this issue, especially in the photos and stories from our recent fly-in to Washington, D.C. There, DPC advocates from across the country met face-to-face with lawmakers to share their experiences and push for change. Moments like these remind us of the difference we can make together.

Thank you for continuing to show up, speak out, and support one another. Living well with kidney disease means embracing the strength, knowledge, and community that surrounds you, and I'm proud that DPC is part of that journey.

Sincerely,

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

ONE DAY AT A TIME

Life Beyond Kidney Failure

By Adrian Miller
DPC Board Member

Thirteen years ago, I thought my story was over before it really began. I was walking with my brother on Super Bowl Sunday in February 2012, following our tradition of visiting neighborhood bars before heading to our parents' house. But that day, I couldn't even make it a block without stopping to catch my breath. I was gasping for air like I'd just run a marathon. Deep down, I knew something was seriously wrong.

The next morning, I asked my sister to take me to the emergency room. When they checked my blood pressure – 260 over 170 – I was on the verge of a stroke. By 3:00 that afternoon, I had tubes in my chest and was connected to a dialysis machine. I didn't even know what dialysis was.

My kidneys had failed due to years of heavy drinking and drug use, combined with dangerously high blood pressure. That day in the hospital, as I faced the reality of what my life had become, I made myself a promise: never again would I touch drugs or alcohol. My family had heard this before and didn't believe me, but I meant it. I have been sober since that day, which is why I believe that having kidney failure saved my life. It helped me discover a new philosophy I live by: just focus on getting through today, and I'll worry about tomorrow, tomorrow.

During my six and a half years on dialysis, I faced serious complications. I had a stroke. I went into cardiac arrest. But I also discovered something powerful – my life didn't have to stop because of kidney failure.

I got a part-time job at 24 Hour Fitness and threw myself into getting healthy. I started by walking on a treadmill for just five minutes. The next week, I pushed for eight minutes. Then I added weights and circuit training. Over time, I lost more than 100 pounds. I measured every ounce of water I drank. I did my best to keep a disciplined diet and eat the same foods every single day that were renal friendly – I wasn't perfect, but I was committed to maintaining healthy habits.

I want anyone reading this to understand: just because you have kidney failure doesn't mean your life has to stop. You choose what you want to do. If you follow the rules – watch your fluid intake, eat renal-friendly foods, take your binders – you can still live productively. Even on dialysis, I was able to coach baseball. It wasn't easy, but it's my passion, and it keeps me connected to something bigger than my illness.

My transplant call came in 2018 while I was actually sitting in a dialysis chair. The nurse looked at me with the biggest smile when Oregon Health & Science University called to say I needed to get off the machine immediately – they had a kidney for me. Everything moved in slow motion until I got to the hospital, then it was like warp speed. I remember getting on the gurney and counting backwards from ten. I probably didn't make it to nine. When I woke up, I had a new kidney.

The surgery wasn't without complications – I had internal bleeding from a cut in the main renal line and needed a second operation. But I made it through.
What keeps me going every day is my family. I have a daughter, two grandsons, and my wife Renée, who I married four years ago. I know they need me here. Going back to my old life is not an option.

My routine isn't for everyone – I went to extremes with exercise and diet discipline. I ate the same renal-friendly foods every day for six years. Being raised in a Hispanic family, giving up cheeses and milk was hard because they're part of our culture, but I did it because I wanted to live.

The most important lesson I want to share is this: kidney failure is not a death sentence. You're not dead when you're on dialysis. However you decide to handle your situation is up to you, but if you decide you want to live, you're going to have to make some changes. Those changes are for the best.

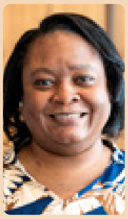
Create routines that work for you. Become a creature of habit with the things that keep you healthy. Follow your doctor's directions as closely as you can. Start small – whether it's exercise, dietary changes, or managing your fluid intake – and build from there.

Every morning when I wake up, I start over. I focus on getting through today, and when tomorrow comes, I'll tackle that too. Thirteen years later, I'm still here. I'm still sober. I'm still fighting. And I'm surrounded by people who love me and need me to keep going.

If you're reading this and you're scared, overwhelmed, or feeling like giving up – don't. Your life doesn't have to stop because of kidney disease. Take it one day at a time, make the changes you need to make, and remember: you get to choose how to live your life, even with kidney failure.

Just get through today. Tomorrow, we'll start again.

Empowerment in My Voice



Quiana Bishop,
DPC Acting President

When my father was diagnosed with End-Stage Renal Disease (ESRD), our family stepped into unfamiliar territory. We didn't know what it meant, how to help, or even what questions to ask. We learned fast – but we learned through fear, frustration, and love. Today, I share our journey not just to honor him, but to help others avoid that helplessness and find hope sooner.

My mother became the caregiver overnight. One minute she was his partner; the next, she was managing

medications, appointments, and emotions that none of us had language for. The strength she showed was quiet but immense. My dad wasn't one to share details – maybe it was his way of protecting us. But I could tell something wasn't right. The strength he'd always worn like armor started to crack around the edges.

I was already managing my own chronic conditions – diabetes and hypertension diagnosed at 19 while at Michigan State University. College was supposed to be my leap into adulthood, but suddenly I wasn't just managing class schedules – I was counting carbs, injecting insulin, remembering blood pressure pills. My independence didn't disappear, but it got redefined.

Before the diagnosis, my weekends looked like any other nineteen-year-old's – spontaneous bar nights, too much pizza and not enough sleep. Afterward, everything changed. I stopped drinking and smoking, spent nights studying and resting. To my friends, I'd become the boring one. But I was planting seeds for the kind of future I knew I deserved.

When my dad developed diabetes, it was my turn to show up. He leaned on me for guidance – asking about medications, meal plans, blood sugar management. Those phone calls became threads tying us together across generations of struggle and strength. For years, he'd been my provider, my protector. Now I had the chance to be that for him.

For my dad, food was art and affection. He was a gourmet chef who poured love into every meal. But managing both kidney disease and diabetes disrupted that rhythm. Meals became equations, ingredients became risks. Even through that struggle, he still tried to make sure we were fed – emotionally, spiritually.

The kidney transplant felt like a second chance. My dad went through intense surgery and came out hopeful. But that vision slipped away when he caught what seemed like a simple cold that spiraled into an infection his body couldn't fight off. After all the battles he'd endured, that's what claimed him.

As a single mother, I am my son's constant – his everyday guide, protector, and source of comfort. Even through my health battles and grief, I've remained steady for him. Because when you're the lighthouse, you can't afford to go dark.

The proudest moment of his life was not just walking across a stage – it was reclaiming it. After battling depression and anxiety during COVID, he walked across the stage at Michigan State University with his classmates, diploma in hand. I was in the crowd, dialysis-weary but determined. When I screamed his name, it wasn't just pride – it was the sound of survival, of legacy, of love. He told me: "I got my strength from you."

I didn't step into the kidney community alone. My mother urged me to be around people who understood the same struggle. Joining Dialysis Patient Citizens (DPC) as an ambassador was a turning point. I found purpose in advocacy, connection in community, and healing in sharing my voice. It saved me from my own darkness.

I wrote an essay about my journey that was selected, sending me to Washington, D.C., representing Michigan alongside other advocates. I went from feeling voiceless to being a voice for all those patients navigating the same struggle in silence.

Being voted Vice President of the Board of Directors for DPC marked a new chapter. I've grown from patient to advocate to leader, guided by the truth that our voices matter.

After one of my speaking engagements, my son hugged me and said, "I'm so proud of you, Mom. You're making me believe I can fight not only for my truth, but for others who can't fight for themselves." My son is transgender, and I knew what all this had led to: not just my voice being heard, but his. I became an advocate for every soul who thinks their truth is too heavy to carry.

My son goes everywhere with me, keeping a watchful eye. When he watches me speak to ESRD patients, caregivers, and legislators, I see something shift in him. He's absorbing the courage, conviction, and compassion. I'm not just teaching him how to advocate – I'm showing him how to love with action.

One day, I'll leave this earth with peace in my heart, knowing the kind of man my son will be. I've raised him to be transparent, strong, kind, humble, and honest. He carries those values forward, and with that, I know my legacy is intact.

I'm not just surviving. I am showing people what purpose looks like in the face of hardship, what advocacy rooted in real life feels like, what motherhood powered by faith and resilience can build.

DPC's 2025 State Advocacy Wins

Pictured left to right: Tyre Gray, Nevada Donor Network, Inc.; Amy Hewitt, National Kidney Foundation; Pamela Zielske, DPC Western Region Advocacy Director; Senator Roberta Lange, sponsor of Nevada SB 292; Ernesto Molmenti, MD and transplant surgeon.

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

DPC achieved key state wins for ESRD patients as several states passed Medigap premium protections during the 2025 session, with legislation in additional states still in play. In addition, several states passed "birthday rule" bills, which aim to allow more flexibility and patient choice for individuals with Medicare Supplement plans by providing a window for Medigap enrollees to change their plans without medical underwriting. As insurers price their plans differently, enrollees may find a more affordable premium for the same plan from a different insurer.

Legislation providing Medigap premium protections for under-age 65 Medicare-eligible ESRD patients remains active in several states as 2025 is the first year of a bi-annual, or two-year session in many states. In Georgia, the House Health Committee passed HB 323 unanimously, with the House of Representatives approving the bill just two votes shy of a unanimous floor vote. The bill, sponsored by Rep. Karen Mathiak, now awaits a hearing in the Senate when session resumes in January 2026. DPC Patient Ambassadors Kristi Flynn and Christopher Richards shared their stories with the House Health Committee, helping legislators understand the unique challenges faced by both kidney transplant and dialysis patients.

Two historic bills that expand affordable access to Medigap passed with overwhelming support in the states of Nevada and Texas this legislative session. Both bills provide affordable access to Medigap plans for dialysis patients who are under age 65.

Sponsored and championed by Nevada State Senator, Roberta Lange (D-NV-7) and signed in June by Governor Joe Lombardo (R-NV), Senate Bill 292 guarantees access to affordable Medigap coverage to Nevadans who are under age 65 and on dialysis. SB 292 fills a devastating gap in Medicare coverage for Nevadans who had neither access to employer based private insurance coverage nor Medicaid. Nevada resident and DPC Patient Ambassador, Chuck Lizer, testified before both the Senate and Assembly Committees, which was instrumental in garnering the nearly unanimous support for this vital legislation.

Under Texas State Representative Ryan Guillen's (R-TX-31) steadfast leadership, House Bill 2516 became public law this past June. This critical legislation guarantees that individuals under age 65 with ESRD or ALS (Amyotrophic Lateral Sclerosis or Lou Gehrig's disease), have access to affordable Medigap coverage. Prior to the passage of HB 2516, many Texans were priced out of Medigap coverage as a result of prohibitively high premiums. Many DPC Patient Ambassadors went the extra mile and submitted written testimony or shared their stories with local media, including Patricia Benavidez-Patel, Joyce Ford, and La Ronda Jones.

Medigap legislation introduced in three states will continue over to the 2026 legislation session, which begins in January. HB 24, sponsored by Ohio State Representatives Jamie Callendar and Bride Rose Sweeney, has been heard in the House Insurance Committee and is awaiting a vote. SB 469 was recently introduced by Michigan State Senator Jeff Irwin and has been assigned to the Senate Health Policy Committee. DPC is gearing up its grassroots advocacy efforts with our Michigan Patient Ambassadors, including DPC Board Chair Quianna Bishop, Board Member Alethea Walls and Patient Ambassador Lacye Ryan. In Massachusetts, companion bills have been introduced in both chambers. In the House, HD 4991 is sponsored by Rep. Thomas Stanley and Sen. Adam Gomez, a kidney transplant recipient, sponsored SD 3096. The Massachusetts bills provide a technical fix that eliminates the exclusion of under-age 65 ESRD patients from access to Medigap coverage. Patient Ambassador Len Gendron spoke with Sen. Gomez prior to the bill introduction during a tour at Len's Fresenius dialysis center. And DPC Board Member Cheri Rodriguez Jones shared her story with Rep. Stanley at the National Conference of State Legislators, held in Boston.

Pictured left to right: Elizabeth Lively, DPC Eastern Region Advocacy Director; Rep. Karen Mathiak, sponsor of HB 323; Christopher Richards, DPC Patient Ambassador; Kristi Flynn, DPC Patient Ambassador

Several states passed legislation allowing eligible individuals to switch Medigap plans or to switch back to Medigap coverage from Medicare Advantage coverage. In Rhode Island, SB 610, sponsored by Sen. Val Lawson, provides an open enrollment opportunity during the Medicare Annual Enrollment Period for Medigap enrollees to switch either to a different Medigap plan, or from Medicare Advantage to a Medigap plan without medical underwriting. And, under-age 65 individuals with Medicare Advantage coverage can switch to every Medigap Plan A policy (meaning Plan A from any insurer writing plans in Rhode Island) without medical underwriting.

Delaware passed SB 71, sponsored by Sen. Raymond Seigfried and Rep. Claire Snyder-Hall, which includes a "birthday rule" allowing eligible individuals to switch to another Medigap policy that provides equal or lesser benefits within 30 days prior or following their birthday date, or for those covered by Medicare Advantage to transition to Medicare supplement policies during the annual open enrollment period. Utah passed HB 258, sponsored by Senator Jake Fitisemanu, which allows Medigap enrollees to switch to a comparable or lower-tier plan without undergoing medical underwriting each year within 60 days of an enrollee's birthday. And Virginia passed HB 2100, a "birthday rule" sponsored by delegates Michelle Maldonado and Irene Shin, allowing eligible enrollees to switch to another Medigap plan with the same benefits within 60 days from their birthday date.

DPC Patient Ambassador, Charles Lizer, testifying before the Nevada Assembly Committee on Commerce and Labor in favor of SB 292.

How can you help? We are always looking for DPC Patient Ambassadors to share their stories by writing letters to legislators, attending meetings with their representatives, 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/).

LIVING WELL with Kidney Disease

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

In the United States, there are over 35 million persons who have chronic kidney disease, which accounts for one in every seven adults. Unfortunately, many millions also have chronic kidney disease and are not aware of the diagnosis.

However, having chronic kidney disease may mean having to alter some of your lifestyle habits to protect your kidney function, but many of us must make sacrifices to stay healthy: limiting fats and high calorie drinks, increasing vegetables and healthy greens, and engaging in regular physical activity.

However, with hypertension and diabetes being the leading causes of kidney disease, it is imperative that these conditions be managed closely to slow the progression of kidney disease. In the early stages of kidney disease, there may be minimal to no restrictions to diet, beyond those of your existing medical diagnoses. This means adherence to your medications as prescribed, checking blood sugars often, and following a diet that is low sodium for better blood pressure control. For many patients, this is an opportunity to take advantage of a dietitian that may be offered by your insurance benefits to assist you with staying healthy.

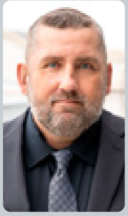
Chronic kidney disease can often be accompanied by fatigue as the disease progresses. However, this may be caused by other factors such as chronic anemia (low blood count), elevated blood sugars, or high blood pressure. By maintaining regular physical activity, you can boost your energy levels, improve your mood, and even lower your blood sugar levels as well as your blood pressure. Simple exercise, such as walking, improves blood flow to legs and muscles, which in turn leads to improved stamina and endurance.

When the weather permits, walking outdoors can be much more stimulating and enjoyable if you are not prone to allergies. It is important to stay hydrated while remembering to keep your fluid limitations within your doctor's recommendation. Consider joining forces with friends or family to engage in walking routines at your nearest indoor mall. Take advantage of the opportunity to have a meal together.

For many patients, the diagnosis of end stage kidney disease can come as a surprise, with many being told of the need for dialysis treatments at the same time as the kidney failure diagnosis. Emotionally, this can be a devastating diagnosis, which can result in depression and difficulty coping with the diagnosis. Know that you are not alone on your journey. Mental health support is always available, whether in person or via telehealth. Whether with behavioral therapy alone or in conjunction with medication, mental health can be treated so that you can improve your mood and get involved with selfcare. Talk to your doctor and get the help you need to enjoy the summers, participate in the fall festivals, and throw snowballs with your neighbor's kids or take that cruise you have on your bucket list.

While having chronic kidney disease may require you to make lifestyle changes, it should not define who you are. Each day is another opportunity to appreciate the 'present' – the gift of another 24 hours that we did not have before. Use it to your advantage: connect to a support community of friends and family, and get involved in the things that bring you joy, whatever that may be. Remember, where there is joy, there is laughter, and with laughter comes the benefits of decreased stress, enhanced heart health, and increased optimism. Try it, you might find that you have a lot to laugh about.

Kidney Failure and Fighting for Our Cause



By Adam Goldstein,
DPC Board Member

When I was 19, I had my whole life planned out, but cancer had other plans. I survived, but not unscathed. The chemotherapy that saved my life also damaged my kidneys. I was diagnosed with kidney failure and began dialysis soon after. For years, I was determined to push forward and live "normally." I got a transplant. It gave me back a sense of independence, a sense that maybe life would stop orbiting around hospitals and lab results. But as many of you know, a transplant isn't always a cure. Mine eventually failed. And so, I returned to dialysis.

That was 2009. Since then, I've spent many, many hours in a dialysis chair. There have been days when I couldn't catch my breath, when I didn't know if I could keep going, when the system – insurance red tape, clinic staffing issues, and other challenges – seemed as draining as the illness itself. I've lived the emotional weight of chronic disease. I've lost a career I loved. I've had to reimagine what "being strong" means.

And yet, I'm still going. And I'm still hopeful.

What keeps me hopeful is that I'm not alone. Along with my loving family, I've found a community. Not just in the nurses and techs at my dialysis clinic who have become part of my life, but in places I didn't expect – like Dialysis Patient Citizens (DPC), an organization that has helped give voice and purpose to patients like me.

DPC understands that hope isn't a passive emotion. It's a daily decision. It's the courage to speak up when issues need fixing. It's the strength to advocate not only for ourselves, but for the next person who walks into a clinic scared and unsure of what comes next.

Through DPC, I've learned that the policies that shape our care are not written in stone…they're written by people. And people can listen. I've met other patients who have turned their pain into advocacy. I've met lawmakers who care. And I've learned that by sharing our stories, we don't just build awareness. We build change.

There are still so many challenges. Too many patients under 65 can't access supplementary insurance coverage. Too many lose their private insurance when they need it most. Too many go without the basic security of knowing their treatments will be covered. But if there's one thing I've learned from my journey, it's that despair is never the end of the story—especially when we face it together.

Dialysis has changed my life. But so has community. So has advocacy. So has hope.

To anyone reading this who's new to dialysis, or who feels isolated or overwhelmed: you're not alone.

Your story matters. And together, we can shape the future for dialysis patients.

CHOOSING LIFE

My Journey with Kidney Disease

By Maria Robinson,
DPC Board Member

I've lived with kidney disease for most of my life. Nearly 30 years ago, I began my dialysis journey. Like so many patients, I was not fully prepared for such drastic change. I had to give up my dream job in order to take care of myself. I felt like I was losing the life I had worked so hard to build. Yet, over time, I realized that kidney failure was not the end of my life, but rather the beginning of a new one. It's one filled with challenges, yes, but also filled with purpose, strength, and community.

When I first started dialysis, I was fortunate enough to have strong coverage. I used Medicare as my primary coverage, had private insurance as a secondary, and received additional help from the National Kidney Foundation. That combination of coverage was critical. It allowed me to access the medications I needed and see the specialists who understood how to manage my condition. I could still make choices about my treatment, and I was able to focus on adjusting to my new normal without the constant fear of how I was going to pay for it. As a board member for Dialysis Patient Citizens (DPC), I've encountered many dialysis patients who aren't so lucky.

Eventually, I had to stop working. When I did, I lost access to my private insurance. I applied for Medicaid as a supplement, but the difference in coverage was hard to ignore. I ended up joining a healthcare group to improve my coverage, but I knew that many patients did not have that option. Without private or supplemental insurance, too many like me must make overwhelming sacrifices, or else fall into medical debt. No one should have to choose to forgo basic necessities to pay for dialysis treatment. But I've encountered many dialysis patients who have to make those tough choices.

Throughout my journey, I've worn many hats. In addition to being a patient, I am also a dialysis technician. That experience gave me a window into the challenges that clinics face every day. I saw firsthand how funding constraints lead to longer hours for staff and fewer resources for patients. I saw how overworked nurses and techs had to stretch themselves thin to provide care. And I saw how patients in rural areas, like those I met when I lived in Georgia, had to drive long distances multiple times a week just to receive the treatment that keeps them alive. When those centers struggle with staffing or outdated equipment, patients suffer.

Despite the challenges, dialysis patients inevitably find ways to live full, meaningful lives. The challenges are just that, challenges, but not insurmountable obstacles. I have worked, raised a beautiful daughter, and now I get to enjoy time with my granddaughter. I volunteer, advocate, and serve on the Board of Directors for Dialysis Patient Citizens. I use my voice to fight for change, because I know how powerful it is when people in our community speak up. Whether it is writing to CMS about inadequate reimbursement rates, urging members of Congress to pass legislation, or helping to lead DPC, the foremost advocacy organization for dialysis patients, I believe that patient voices need to be heard.

Dialysis is a tool to keep me alive. But I do more than survive. I thrive. I live a fulfilling, productive life. I hope that my story shows how kidney disease does not define us. It shapes us, yes, but it also reveals what we are capable of.

To every patient reading this who feels overwhelmed, I want you to know that you are not alone. There is a community here that understands what you are going through.

We have chosen to live, fight, advocate to lawmakers in DC. We work, we raise families, we support one another, and we keep moving forward. Kidney disease may be part of our story, but it is not the whole story. Never give up.

I did not choose kidney failure, but I have chosen how to face it. Every day, I choose life.

FROM FLATLINE TO FRONT LINES

A Dialysis Warrior's Fight for Every Patient's Future

By Arthur Hill,
DPC Board Member

"When Death Couldn't Stop Me, I Knew I Had Work to Do"

When I first learned I had Goodpasture's disease – a rare condition that would forever change my life – I had no idea I was about to embark on a journey that would reveal depths of strength I never knew I possessed.

September 2010 marked the beginning of what I now call my awakening. Despite feeling unwell, I pushed forward with determination, traveling to Mississippi for work. My body was sending me urgent signals, but I was too focused on my responsibilities to listen. Two weeks later, when I finally sought medical attention, I discovered my kidneys had failed - the diagnosis: End Stage Renal Disease (ESRD). What followed was emergency heart surgery and the beginning of my dialysis journey.

In those critical moments – when my heart stopped twice, once in the ambulance and once in the hospital – I experienced something profound. Each time I returned, I felt chosen for something greater. These weren't just medical emergencies but transformations that would fuel my purpose.

As a self-employed individual recently deciding to forgo health insurance, I thought I understood sacrifice. But ESRD taught me lessons no textbook could: resilience in financial uncertainty, strength in vulnerability, and incredible support systems that emerged when I needed them most.

Dialysis became more than a treatment; it became my classroom. In those chairs, surrounded by fellow warriors fighting the same battle, I discovered an extraordinary community. We share more than medical procedures; we share hope, laughter, and an unbreakable bond forged by our determination to thrive.

This experience ignited something powerful within me. When I stood before Indiana lawmakers advocating for Senate Bill 215 – legislation that would reduce Medigap premiums for dialysis patients under 65 – I realized my voice could catalyze change. That advocacy moment led to one of my greatest honors: joining the Dialysis Patient Citizens (DPC) Board of Directors, where I fight for every patient's right to live with dignity and hope.

The recent Supreme Court ruling threatening our access to employer-sponsored health plans strengthened my resolve. Having experienced firsthand the lifeline private insurance can provide, especially during those critical early months, I've become a fierce advocate for the Restore Protections for Dialysis Patients Act. This isn't just policy – it's about preserving hope and choice for every patient and family.

What I've learned on this journey is revolutionary: we are not defined by our diagnoses. Every dialysis session is an opportunity to inspire, connect, and make a difference. Our scars tell stories of survival. Our treatments are reminders of our incredible resilience. Our community is proof that no challenge is insurmountable when faced together.

To every patient reading this, to every family member walking alongside a loved one, to every caregiver making a difference: you are part of something magnificent. We are warriors, advocates, and living proof that medical challenges cannot diminish the human spirit.

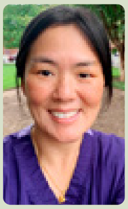
Your story matters. Your voice has power. Your presence in this world makes a difference.
Together, we don't just survive – we triumph. Together, we transform challenges into opportunities. Together, we ensure that every person facing kidney failure knows they are valued, supported, and never alone.

This is our movement. This is our moment. This is our victory.

Keep fighting. Keep believing. Keep inspiring.

The best chapters of our stories are still being written.

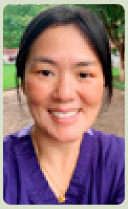
Kidney-Friendly Recipe



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 super quick and simple recipe that takes advantage of all the summer squash that's in season!

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 súper rápida y sencilla que aprovecha todas las calabazas de verano que están en temporada.

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.*

Zucchini Squash Bake

This recipe was adapted by Collette Powers, MA, RD, LDN, ACSM EP-C, from Our best summer casserole recipes, April 2017, Taste of Home.

Prep Time: 00:25
Cook Time: 00:10
Total Time: 00:35
Makes 6 Servings

Ingredients

- 2 T. extra virgin olive oil
- 2 med. zucchini, cut into 1/4-inch slices (approximately 2 c.)
- 1.5 med. yellow summer squash, cut into 1/4-inch slices (approximately 2 c.)
- 2 shallots, minced
- 1/2 tsp. dried oregano
- 1/4 tsp. coarsely ground pepper
- 4 garlic cloves, minced
- 1 c. panko (Japanese) bread crumbs, divided
- 1/2 c. grated cheddar cheese, divided

Instructions

1. Preheat oven to 450° degrees F.
2. In a large skillet, heat olive oil over medium heat; add zucchini, yellow squash and shallots. Sprinkle with oregano and pepper.
3. Cook, stirring occasionally, until zucchini and squash are crisp-tender, 4-6 minutes.
4. Add garlic; cook 1 minute more. Remove from heat; stir in 1/2 cup bread crumbs and 1/4 cup cheese.
5. Spoon mixture into a greased 11x7-in. or 2-qt. baking dish. Sprinkle with remaining bread crumbs and cheese.
6. Bake until golden brown, 8-10 minutes.

Nutrition Facts (Per Serving)

Sodium: 106 mg
Potassium: 221 mg
Phosphorus: 83 mg

Gratinado de Calabacín y Calabaza

Esta receta fue adaptada por Collette Powers, MA, RD, LDN, ACSM EP-C, a partir de Our best summer casserole recipes, abril 2017, Taste of Home.

Tiempo de preparación: 25 min
Tiempo de cocción: 10 min
Tiempo total: 35 min
Porciones: 6

Ingredientes:

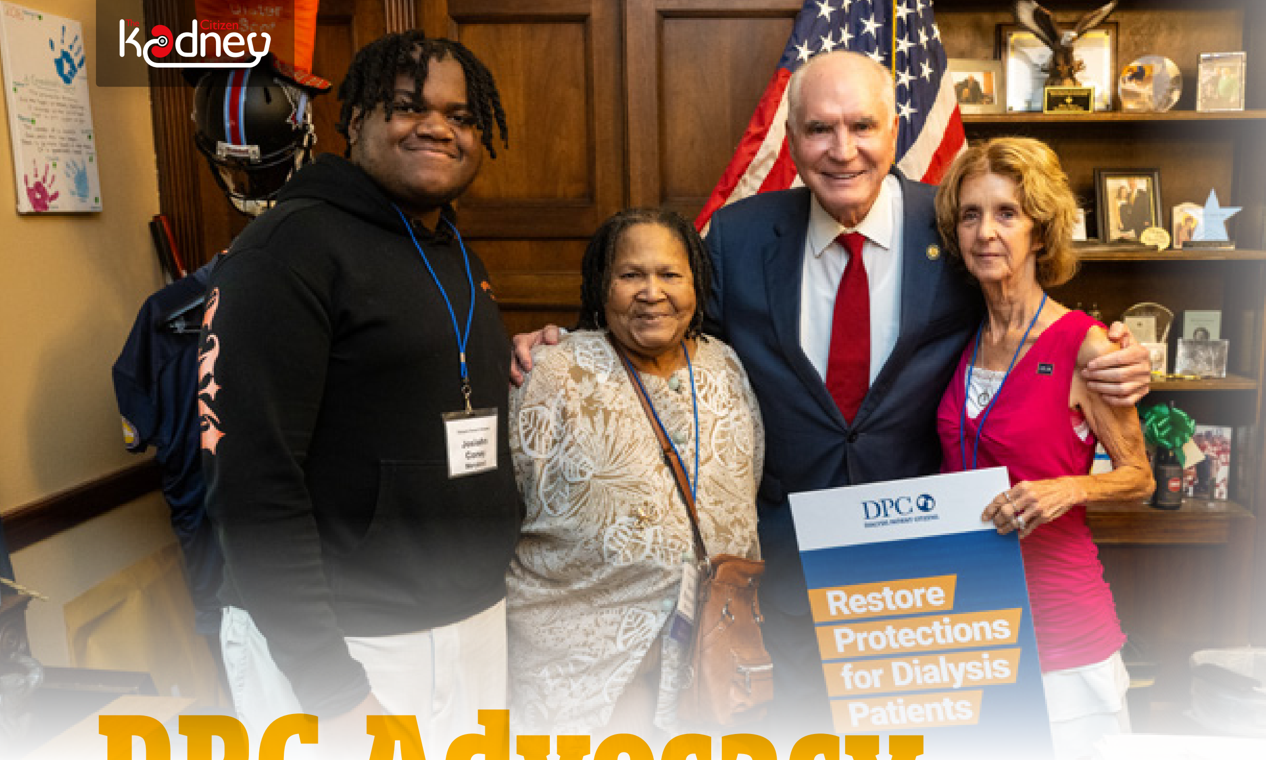
- 2 cucharadas aceite de oliva extra virgen
- 2 calabacines medianos, cortados en rodajas de ¼ de pulgada (aproximadamente 2 tazas)
- 1½ calabaza amarilla mediana, cortada en rodajas de ¼ de pulgada (aproximadamente 2 tazas)
- 2 chalotes, picados finamente
- ½ cucharadita orégano seco
- ¼ cucharadita pimienta negra molida gruesa
- 4 dientes de ajo, picados finamente
- 1 taza pan rallado japonés (panko), dividido
- ½ taza queso cheddar rallado, dividido

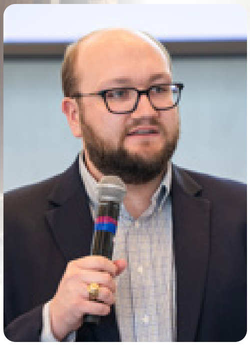
Instrucciones:

1. Precaliente el horno a 450 °F (232 °C).
2. En un sartén grande, caliente el aceite de oliva a fuego medio y agregue el calabacín, la calabaza amarilla y los chalotes. Espolvoree con orégano y pimienta.
3. Cocine, revolviendo ocasionalmente, hasta que el calabacín y la calabaza estén tiernos pero aún firmes, aproximadamente de 4 a 6 minutos.
4. Añada el ajo y cocine por 1 minuto más. Retire del fuego y mezcle con ½ taza de pan rallado y ¼ taza de queso.
5. Vierta la mezcla en un molde para hornear de 11x7 pulgadas o de 2 cuartos de galón (2 qt.) previamente engrasado. Espolvoree con el pan rallado y el queso restantes.
6. Hornee hasta que esté dorado, por 8 a 10 minutos.

Información Nutricional (por porción):

Sodio: 106 mg
Potasio: 221 mg
Fósforo: 83 mg





DPC Advocacy Day 2025 When Patients Lead, Policy Listens

By Yolonda Brisbane,
DPC Grassroots Manager

From July 12–15, 2025, the nation's capital was infused with a powerful sense of purpose and unity as Dialysis Patient Citizens (DPC) welcomed 36 extraordinary Patient Ambassadors—dialysis patients, transplant recipients, and family members of those living with or lost to End Stage Renal Disease (ESRD)—to Washington, D.C. for our Annual Congressional Advocacy Day.

Our time together began with preparation and purpose. Patient Ambassadors entered a space of belonging that offered state-of-the-art meeting rooms and delicious kidney-friendly meals—nourishing both body and spirit. This setting became the heart of meaningful conversations, new friendships, and genuine camaraderie.

We deepened our work through community-building and in-depth advocacy training, led by our expert partners at Advocacy Associates, a former official from the Department of Health and Human Services, and a Capitol Hill staff member. Ambassadors gained valuable policy knowledge, and tools to elevate their voices—to tell their stories in ways that educated, inspired, and motivated.

Moreover, the training equipped our Patient Ambassadors to confidently participate in 85 coordinated meetings with congressional leaders and staff, representing 24 states, bringing the voice of the ESRD community directly to our nation's policy makers.

Beyond the training and advocacy work, Patient Ambassadors enjoyed exploring Washington, D.C.—taking in its historic landmarks, vibrant culture, and local cuisine. For many, it was also their very first opportunity to experience the nation's capital, making the trip both impactful and unforgettable.

Determined to protect access to dialysis care, Patient Ambassadors championed the RESTORE Act (H.R. 2199 / S. 1173) and raised awareness of the soon-to-be-introduced Kidney Care Access Protection Act (KCAPA). They also encouraged lawmakers to join the House Kidney Caucus, helping amplify the voice of the ESRD community and Dialysis Patient Citizen's commitment to building meaningful relationships with our leaders on Capitol Hill.

> ***"This work is important to me due to the high numbers in kidney disease and chronic health conditions overall. One voice can have an impact, but many voices together, leads to action."***
> ***— Porothea Dennis, Ohio Patient Ambassador***

Health and Hospitality

Dignity in Every Detail

To ensure everyone could participate fully and safely, 12 in-center dialysis patients received treatment at DaVita Union Plaza, our host dialysis center in D.C. Thanks to the exceptional staff, patients received continued care that allowed them to remain engaged throughout the event without missing a beat.

"I have dealt with kidney disease my entire life and Advocacy gives my life purpose. I can meet with people who are going through similar things, and we are changing the lives of dialysis and kidney patients by fighting for them and making a difference with Congress." — Kendra Deike, Iowa Patient Ambassador

Our Work Does Not Stop at Advocacy Day

DPC keeps the empowerment and energy going year-round through monthly events—open to anyone who wants to learn, connect, and be part of a community that truly reflects the patient voice. Our Kidney Chat Support Calls, Patient Ambassador Meetings, Facebook Live sessions with Dr. Velma Scantlebury, and our Facebook Live Roundtable Talk Series all offer connection, support, and information for patients, families, and care partners. Even in these spaces, our Patient Ambassadors serve and lead.

In addition, our Patient Ambassadors work with our public relations partners at Firehouse Strategies to write Letters to the Editor and have them published in their local newspapers—bringing awareness about kidney disease to their respective communities and lawmakers.

To every Ambassador who traveled to D.C., told your story, and stood proudly in your truth—thank you. You are the heart of this work, your voice is the difference, and it is my honor to serve alongside you.

To learn more about Dialysis Patient Citizens, or join our membership and Patient Ambassador community, contact us at 866-877-4242 or www.dialysispatients.org. There is a space for your voice and your story.

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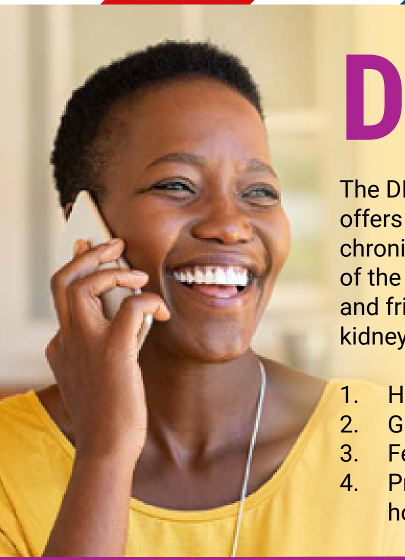

DPC Kidney Chat

Connecting by phone with other kidney patients and their families

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

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

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

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

Learn more and RSVP at www.dpcedcenter.org

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

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