

# The Citizen Kadney

Issue number 18

A publication of Dialysis Patient Citizens (DPC) Education Center



# EMPOWERMENT



# President's Message



**G**reetings to all of you reading our latest edition of The Kidney Citizen. We extend our heartfelt gratitude for your support, particularly as we celebrate DPC's 20th anniversary. It is our hope that the information, insights, and inspiration we share in this edition resonate with you and foster positive change in your lives.

At DPC, we empower patients, and The Kidney Citizen helps us advance that mission. As an End Stage Renal Disease (ESRD) patient myself, I know personally how challenging and overwhelming it can feel sometimes. That is why the information and resources we share in The Kidney Citizen are there to help light the way. In this issue of The Kidney Citizen, readers can find educational information from leading health experts, uplifting stories from other ESRD patients, updates about DPC's legislative advocacy efforts, and more.

**Kidney disease is a journey, and we hope that The Kidney Citizen provides you with the support you need, as we want you to live your best life. From basic healthcare information to online courses and personal counseling, the DPC Education Center works to provide the support kidney patients need to thrive**

Kidney disease is a journey, and we hope that The Kidney Citizen provides you with the support you need, as we want you to live your best life. From basic healthcare information to online courses and personal counseling, the DPC Education Center works to provide the support kidney patients need to thrive. Kidney disease is not a death sentence – patients just need a little help along the way, and the DPC Education Center works to provide that helping hand.

Looking toward the future, we are excited to keep innovating and creating new tools for patients. We hope you will continue to read The Kidney Citizen and follow the DPC Education Center through our social media platforms for all of the latest information and educational opportunities.

Merida Bourjolly,  
President of DPC Education Center Board of Directors

# CEO's Message



**W**e are thrilled to celebrate our 20th Anniversary at Dialysis Patient Citizens (DPC) this year. It has been an incredible journey, and we are so grateful for your efforts to help us grow into the organization we are today.

It is easy to forget that DPC was formed when a handful of dialysis patients came together to advocate for their care. They often felt ignored as transplant issues were the main focus of the kidney community at the time. So, to ensure that DPC always prioritized the needs of dialysis patients, our bylaws require the President, Vice President and a majority of our Board to be current dialysis patients.

That handful of dialysis patients has now grown into an extremely effective patient advocacy organization with 35,000+ members working together to advance public policies to improve their lives. I consider myself truly fortunate to work with so many amazing advocates on a daily basis, helping them tell their stories at the state and federal levels. We work to make sure that policy makers treat them like the extraordinary people they are and not just a line-item in the budget.

We continue to work to improve dialysis patient quality of life, by empowering patients through advocacy and education. So, ten years ago DPC's patient-led Board voted to create our affiliate organization the DPC Education Center. They wanted DPC to remain focused on the difficult advocacy work that was necessary to move critical legislation. However, they felt it was equally important to educate patients and empower them in their own care, and they wanted the two organizations to stay focused on their work. The Board did not want DPC to try to do everything, just because it was gaining momentum.

Since that time, DPC's Education Center has worked tirelessly to equip patients with the information and support they need to thrive. An ESRD diagnosis can be confusing and scary in equal measure, and we strive to clear the confusion. We provide pamphlets, one-on-one support, on-line tools and resources, as well as The Kidney Citizen magazine to connect with patients about treatment options, lifestyle management, and advocacy opportunities. Education empowers patients to confront important health decisions with confidence.

We want to give every kidney patient the medical and moral support they need to continue to live a good life. We have made significant progress, but there's still much more work to do! Thank you for your continued support of DPC and the DPC Education Center. We look forward to building on our efforts. Let's see what we can do together in 2024.

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



# Knowledge to Empowerment



**By Nancy L. Scott,**  
DPC Education Center  
Project Manager

As I sat on the side of my hospital bed on a cold night in March of 2004, my heart was broken and it felt as though my time on the planet was almost over. I had just been diagnosed with **END STAGE RENAL DISEASE**.

The word “end” means a final part of something, and I thought that something meant me. I had just retired and planned to enjoy life and travel as much as possible. These dreams had come to an end! (Little did I know at the time, the dreams were just beginning!) The nephrologist had just left the hospital room and said she would be back early in the morning to insert a catheter and that I would have my first dialysis treatment.

Dialysis! Me! I must admit that I thought about leaving right then and there. Instead, I chose to cry myself to sleep and hoped that by the time the morning came, I would be told that the diagnosis

was incorrect. Not! The nephrologist came early in the morning and by 7:00, I was officially on dialysis. Depression, frustration, anger, and isolation—all of these emotions were felt. I was allowed to dialyze at the hospital as an outpatient for three months before I transitioned to a dialysis center. It was very different, but the staff was efficient and patient. I was still depressed, angry, frustrated, and still felt very much isolated from reality.

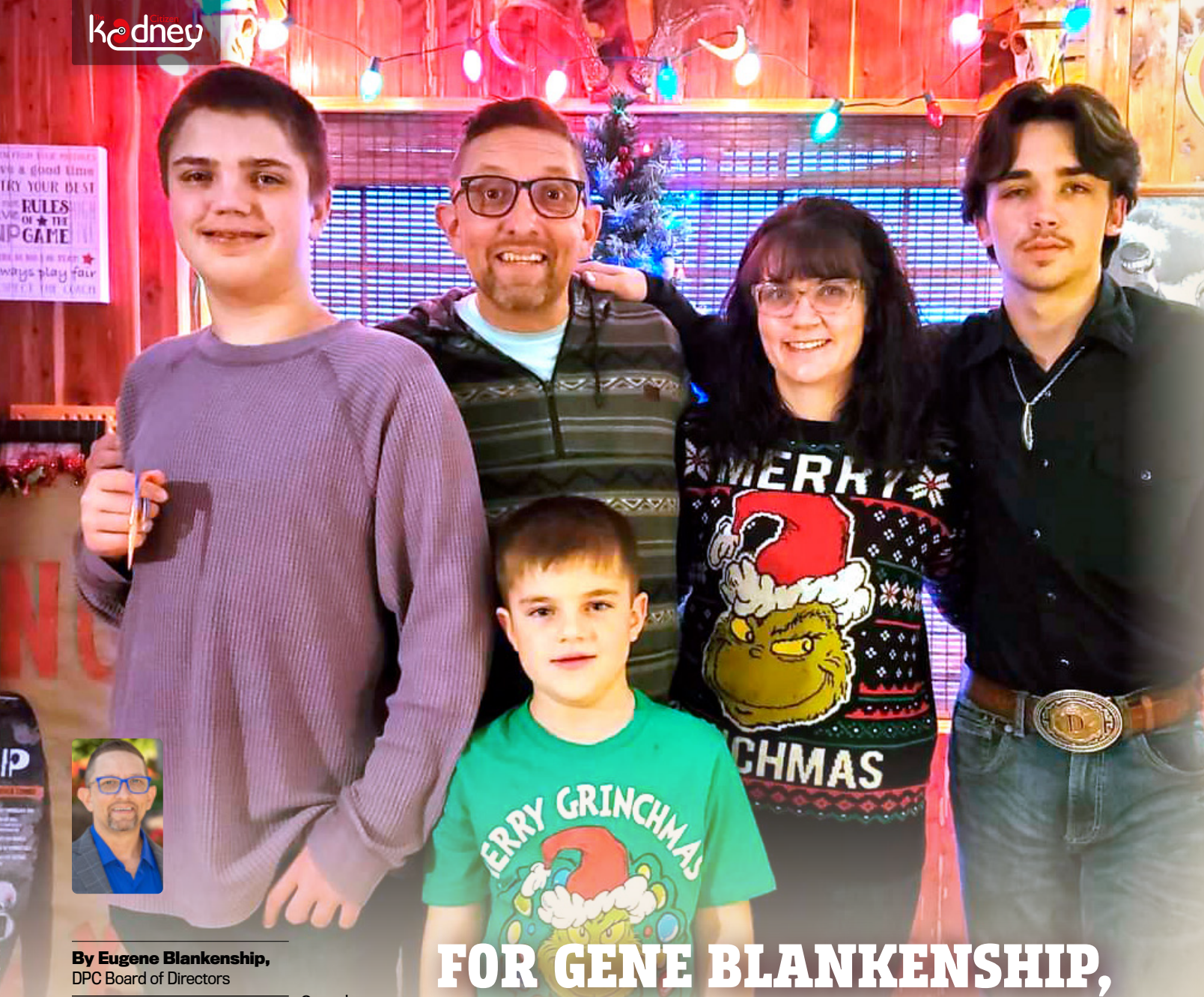
Then, I began to educate myself about the world of dialysis and how I could improve my quality of life and help others on this same journey. I did dialysis; I did not let it do me in! I started a support group. It was the only support group in the area; therefore, many other patients came from near and far.

The dialysis center even purchased lunch for us, and the group’s session was called “Lunch and Learn”. We supported each other; neurologists, nutritionists, and other medical professionals were invited. We laughed, cried, and ate—but most of all we learned about how to

survive while on dialysis. We became empowered. It did not stop there for me!

One day as I was dialyzing, the nurse practitioner stopped by my chair. She told me about an organization called DaVita Patient Citizens—now known as Dialysis Patient Citizens. She thought that it would be a good idea for me to experience advocacy on another level. I called DPC and spoke to the Executive Director at that time (2007).

The nurse practitioner had already briefed him that I would contact him. He knew that I spoke at many renal events and asked if I could go to Pittsburgh for a speaking engagement that he had been asked to attend but he had a conflict in his schedule. Of course, I was delighted to go and that is how I joined DPC! As I got more involved with DPC, I became a patient ambassador, a board member, went to Washington, D.C. numerous times, advocated on Capitol Hill, became President of the DPC advocacy side, and then President of the education center. I had the opportunity to be invited to the White House and to speak before the President of the United States. All of these opportunities are not mentioned to receive accolades but to emphasize how knowledge can lead to empowerment. I had received the right to help to empower others because I became empowered. I no longer felt isolated—I served and serve a community that I fit in because we are all on the same journey. Knowledge is empowerment!



**By Eugene Blankenship,**  
DPC Board of Directors

Gene has had a front row seat to life with kidney disease for as long as he can remember. His entire family has been affected by kidney disease, and he was diagnosed himself in 2003. While it has come with challenges, Gene has continuously pushed forward, bolstered by the loving support of his family and those in the dialysis community he's met along the way.

After three years on dialysis, Gene was finally able to receive a kidney transplant this year. Persevering through dialysis treatments can take a toll, but Gene learned firsthand his ability to overcome obstacles with the help of his support system.

After Gene started dialysis, he began attempting in-home treatments, but eventually transitioned to in-center, where he's had a positive experience and seen how differently patients handle their treatments.

## FOR GENE BLANKENSHIP,

# Family is Everything

While Gene has always been eager to speak up when things aren't right, he learned that many dialysis patients don't have that same level of comfort, and he used his time in the clinic to engage with other patients and inspire them to be courageous when times get difficult. Gene's compassion for fellow members

of the dialysis community did not go unnoticed.

Gene has been deeply touched by the support he's received at the dialysis clinic, often from complete strangers. His biggest source of strength and support throughout dialysis have been

his wife, his sister and his children, but the relationships and encouragement Gene developed at the clinic have also been extraordinarily uplifting, acting as an extension of his family.

This support system gave Gene the courage to persevere through his dialysis treatments until he finally received a kidney transplant, something he is certain would not have been achievable on his own.

Gene and his family love traveling, going to the beach, fishing, fairs, and anything they can do together. They've already gone to Disney World and Universal Studios and have made a million memories together with Gene on dialysis and are even more excited to continue making them without having to plan around Gene's treatment schedule.

Gene has also found an incredible support system through his job with the Oklahoma Public Employees Association, which has been a source of strength on his journey with kidney disease.

Not only has his employer been very respectful of his condition, but his position allows him to help employees across Oklahoma, something sharing his experiences on dialysis adds great value to. Sharing this perspective outside of the dialysis community is something Gene enjoys, and he's comfortable speaking about his experiences at meetings and with colleagues. People will often come up to Gene after a meeting to share that they are close with someone who has kidney disease, and that it's very valuable for them to hear his story.

While Gene has always appreciated the empathy he's received from those who hear his story, he does not want it to turn into people feeling sorry for him. He knows that his health and his life are in his own control, and as he says, "there ain't no give up in me!"

When asked his main advice for those starting dialysis, Gene said, "don't let the worry take up residence in your mind. It's not as bad as you think, and it's not going to be as bad as you think. You can live a good life on dialysis."

Gene is an advocate for educating yourself on the effects of kidney disease once you get diagnosed. There's so much false information out there, and he believes it's very important to research,



talk to your doctors, and understand that your circumstances might not be as bad as you think they are.

Of course, Gene does recognize the challenges of dialysis, understanding the importance of being honest with yourself and how your lifestyle will change. But above all, he is adamant in meeting these challenges head-on as soon as they arise, otherwise they will compound and become much more difficult to overcome.

When it comes to overcoming the daily challenges, Gene says, "Push through, get to the other side, and collect those small victories."

DPC has also been a source of inspiration for him, as they've done a great job of raising awareness and providing opportunities to connect with others in the kidney disease community. Through DPC, Gene gets to speak weekly with a patient from Ireland, sharing their experiences and strengthening the bonds of their powerful community.

Gene is also grateful for the information and resources DPC provides patients, including how they can help themselves and be in charge of their own healthcare. When it comes to kidney disease, Gene says "bad advice is deadly advice," and having reliable sources of information is so critical.

Gene has had an extremely fulfilling life while managing his kidney disease and dialysis treatments. He attributes this to his incredible family and his support system in the dialysis community, serving as a great team helping him juggle all of the daily responsibilities of working a full time job, being a husband and father, and having kidney disease.

As Gene shows, dialysis is much easier to overcome with a strong support system, and the team at DPC is eager to help. If you would like to speak with any of our advocates, or learn how to become one yourself, feel free to get in touch with us at [www.dialysispatients.org](http://www.dialysispatients.org) or by calling (866) 877-4242. We can't wait to meet you!



**Merida Bourjolly**

# Taking Control of Her Care and Finding Meaning Through Advocacy

came with big adjustments. She did her best to continue working five to six days a week like she had before, but found she was increasingly tired while styling her clients' hair. Eventually, she had to scale back and only work on the days she did not do her dialysis treatments.

Adjusting her work schedule didn't mean Merida slowed down, though. It was important to her to keep moving forward, to stay active, and to not feel sorry for herself. She still wanted to be able to go to her daughter's plays, travel when she was able, and support her family. For Merida, that meant cooking at home as part of a food preparation business that helped raise money when she wasn't able to go in for work.

Merida's friends also helped her to stay active. They frequently called to check in, made sure she stayed on top of her treatment schedule, challenged her to

**By Merida Bourjolly,**  
President of DPC Education  
Center Board of Directors

Merida Bourjolly had a kidney removed when she was just three weeks old,

though it wouldn't be until much later that her experience with dialysis would begin.

By then, she already owned her own business and had both a teenage daughter and her mother to take care of at home, which meant starting dialysis





stay positive, and kept her from feeling lonely when the mental toll of dialysis treatments started to weigh on her.

She also found immense support from the rest of her family. After she began dialysis, her brother would ask her about the treatments she was receiving and how they affected her body, always encouraging her to learn more and take a proactive approach to her care. However, when Merida asked other patients some of the questions her brother had asked her, she found that answers were hard to come by. She knew she needed to learn more.

Nurses provided some answers, but Merida wanted to go more in-depth. She began taking night classes to become a dialysis technician at a local university. On the days that she had treatment, she would take a bit of time to recover and then head to class, where she learned what she needed to know in order to take charge of her care and have confidence in the decisions she made. It also helped her to teach her family about what she was going through so they could better understand it as well.

While she was on dialysis, Merida also was working hard to find a transplant. She was listed for one in New York, but also was aware that the state had long wait times, sometimes longer than 10 years. Once she found out she could get on the waitlist in Pennsylvania, where wait times were usually shorter, she transferred a portion of her hours there to boost her odds. Some of her family members were also tested as possible donors, but none qualified.

Two and a half years later, the call came from Pennsylvania that she could finally receive her transplant. She noticed the difference immediately after the surgery. She felt stronger and more motivated, and found that food even tasted better. She felt so much better, in fact, that the transplant team had to tell her to take it easy while she recovered from the surgery to avoid putting too much strain on her body.

As she recovered, Merida was also able to return to work full-time and be more available to her family in ways that were more difficult before. She no longer had to schedule events around her appointments, and never had to leave a family function early to receive treatment.

Merida has also dedicated herself to becoming an advocate for dialysis patients. When she was undergoing treatment, she felt it was hard to relate to the other patients at her clinic, as she was the youngest there. When she went in search of a support network within the dialysis community, she found Dialysis Patient Citizens (DPC).

At DPC she found people who were not only supportive and had the information she was looking for, but who were also fighting for dialysis patients on a different level than she had seen before. She wanted to engage more with the policies affecting patients and push for laws that both made patients' lives easier and made coverage more accessible.

Participating in her first Advocacy Day in 2017 was just the start for Merida at DPC. Now, she is a member of the DPC

Board of Directors as well as president of the Board of Directors of the DPC Education Center.

As part of her advocacy, Merida helps patients by encouraging them to stay positive. She wants patients to understand that there will be days they aren't feeling well, and it is ok to feel that way, but it is also important to find ways to pick yourself back up.

For Merida, that meant continuing to work when she could and taking a proactive part in her care. If patients are working a physically strenuous job that is more difficult to continue while on dialysis, then she encourages patients to find a hobby they love, find ways to stay active, and work with a social worker to understand the wide range of travel possibilities while still making arrangements for dialysis treatment.

Most importantly, she encourages patients to be their own biggest advocate. It is important for patients to speak up when they need to, teach the people around them what they are going through, and avoid falling into a place where they feel helpless. Life on dialysis can be incredibly fulfilling, and understanding that is crucial for staying positive.

Do you want to join Merida in advocating for dialysis patients to ensure they can lead the lives they want to live? We would love to hear from you! If you would like to speak with any of our advocates, or learn how to become one yourself, feel free to get in touch with us at [www.dialysispatients.org](http://www.dialysispatients.org) or by calling (866) 877-4242.

# Ask the Doctor



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

## 1. Will a transplanted patient who receives a kidney from a diabetic individual become diabetic?

Diabetes results from a lack of the ability of your body to produce/and or use insulin effectively. If a kidney is used from a deceased donor who is diabetic, it is often biopsied to make sure that the kidney is not damaged from diabetes. Some transplant patients are at risk of becoming diabetic due to the anti-rejection medications used, including the use of steroids to treat rejection episodes. Therefore, your risk of becoming diabetic is related to your underlying family history, weight gain, and medications used after the transplant, not the transplanted kidney itself.

## 2. Is self-cannulation recommended or not recommended for dialysis patients?

If you are on hemodialysis, you actually have a right to insert your own needles, or self-canulate. Self-cannulation can be done by any patient who wants to participate in their own care and treatment. Once you receive the appropriate training and demonstrate competence, then you can decide if you want to do so or not. Patients on home dialysis are taught the technique and are successful in carrying out their own dialysis insertions.

## 3. Once on dialysis, always on dialysis. Is this statement true or false?

Some patients can undergo acute dialysis because of a short-term injury to their kidney function, referred to as acute kidney injury. This is often sudden and is common in patients who are hospitalized, in intensive care, or even older patients with underlying medical issues. In many

of these cases, once the underlying issue is corrected, there is often recovery of kidney function over time.

Other causes can be allergic reactions to drugs (interstitial nephritis), overwhelming infections, or even blockage to your kidneys such as kidney stones or prostate issues.

On the other hand, chronic renal failure is a slow process, often unrecognized, and results in significant scarring of the kidneys resulting in the need for long-term dialysis. Biopsies of the kidneys in these situations often show overwhelming scarring and the absence of the functional components that do the work of the kidneys. In these cases, the need for replacement therapy is permanent and can be eliminated only by kidney transplantation instead of long-term dialysis.

## 4. Is it okay for transplant patients to skip anti-rejection medicine every other day?

It is never okay to skip anti-rejection medications. These medications are

given to protect your transplanted organ, and the dosing is based on how long the drug stays in your system. By taking your medications as prescribed, you keep the blood dosages at the desired level that protects your transplanted organs. When you skip doses, you leave your transplanted organ unprotected with much lower levels of the anti-rejection medication, giving your killer white blood cells a chance to sneak in and attach to your transplanted organ. While this will not be evident at first, it allows for the buildup of scar tissue, which slowly replaces the working sections of your kidney, leading to chronic destruction over time. This will reduce the life of your transplanted kidney in a manner that is often not salvageable.

If you cannot afford to take your medications every day, speak to your transplant coordinator about cheaper options that may be a better choice. There are also medications that can be taken once a day.





# How Transplant Changed My Life Forever



**By Adrian Ropp,**  
DPC Patient Ambassador

It was Christmas and I was home to visit my parents for the holidays. It was the first time I had traveled there in a year without my dialysis equipment or a schedule to visit a clinic. A brave police officer named Albert had recently lost his life, but he had registered as an organ donor. Because of this, I was celebrating a Christmas I had not expected. It happened (and believe me, it is a story that would take this whole article) that my savior's family - his wife Lori and their three children, lived in my parents' hometown. We had made plans to meet for the first time during my trip and my wife, Jennifer, and I pulled into her driveway with some amount of nervousness and excitement.

The nervousness was not warranted. Lori could not have been kinder, and we talked for hours. At one point, Lori asked a very important question. Sitting across from us in her cozy living room, she inquired, "How has your life changed since the transplant?"

The standard things applied here. I no longer had a kitchen full of dialysis supplies delivered every month and I didn't have to carry a heavy suitcase with the machine. I was gaining weight again, my health problems were receding and I wasn't on a fluid restriction. (Truth be told, it took me months to feel comfortable gulping water again.) My blood pressure dropped into the normal range, I didn't have swelling in my legs, and my energy was improving. I had a wonderful physical change.

What is less obvious is the ways it change my soul. I often tell people I

am not the same human being I was before my second chance. For one thing, I appreciate everything more. I knew I only had a few weeks left and I had been saying goodbye to people, mourning the experiences I wouldn't have with my family, and trying to figure out how to talk to my Jennifer about some really serious plans that needed to be made. The gratitude is abundant and takes so many forms. I think often of the nurses at my dialysis clinic and how they kept me positive when the chips were down. (I still visit them every so often, they are family now.) Trees and flowers have bright colors and every smell and taste in the world is something amazing and wonderful.

I also had a chance to reassess my priorities. I didn't spend nearly enough time making memories with my wife and far too much time living to work. With this new lease on life, I've swapped that. Time is the currency we all have to spend, and I want to spend mine on memories, not things. We talk often about experiences we want to have and places we would love to see. I think it helped our relationship and rekindled some of the love we had for each other. After all, I didn't go through the tough times alone. I always had a partner ready to pick up the pieces.

I think often about people on dialysis and their need for heroes. I remember sitting in the chair in clinic and staring at the exit door, imagining some team on the other side of that door was working diligently to find my match. I want to be the advocate they're hoping for. I know that only 1 in 3 people who need a transplant receive one, and I made a vow that in my lifetime that number is going to improve. I find groups like Dialysis Patient Citizens and volunteer. I share my story. I even

created a Facebook group where I share raw and important details of my journey. I believe that personalizing this story will make more people want to donate.

What is a life worth? Everyone is precious and deserving of the experiences of this world. For me, I have created stories for Disney, Pixar, Star Wars, and Marvel, and drawn characters such as Bullwinkle, Casper, and Underdog. My life saving gift means I have another chance to spread joy and kindness to the world with my art. I am more driven than ever to do so and if it wasn't for people like Albert and Lori, my artistic contributions to the world would have been cut short.

I'm still learning a lot about myself, but I'm so excited to do so now. I'm more confident in making life choices because I know what I value. The other stuff is just noise. I've made some difficult choices to not associate with people who don't value me. And, importantly, I've learned that I get to set my worth. I don't need to rely on others to determine that.

Organ donation and supporting measures to increase dialysis patient care are amazing and heroic gifts that can, and do, change lives. Everyone has a story. Everyone is a son or daughter, husband, wife, or best friend to someone. My wish is that every kidney patient gets a chance to value those connections as they should.



# DPC's 2023 Advocacy Day



**By Megan Hashbarger,**  
DPC Vice President of  
Government Relations

In October 2023, DPC held its' annual Advocacy Day in Washington, D.C.

This year, we were able to bring over 50 patients to D.C. from 23 different states. Unfortunately, due to Covid complications and for the best safety of our patients, we did end up having to make their Hill meetings virtual. Despite this, we were still able to meet with almost 60 Congressional offices about issues facing dialysis patients such as the need for access to Medigap and private insurance. We were also able to host a day of

advocacy training for our patient ambassadors, bringing in stakeholders from various sectors, including Chris Bowlin (Executive Director, Head of Public Policy and Government Relations, Cormedix) and Colin Roskey, (Executive Director, Kidney Care Partners) to represent the kidney community, Melanie Egorin (Assistant Secretary for Legislation, (ASL) U.S. Department of Health and Human Services (HHS)), and The Honorable Tom Reed (Former Member of Congress, NY-23rd) to give their perspectives of working on kidney priorities. We look forward to hosting this year's Advocacy Day in May – this is a great experience for our patients and a wonderful opportunity to elevate the ESRD patient perspective.



# Kidney-Friendly

# Recipes



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

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



## Broccoli Salad

This recipe was submitted by Sandra Crum for the **DCI Kidney Cookbook**

### **Ingredients:**

*Makes 10 Servings*

- 4 c. broccoli cut into small florets
- 1 large carrot, peeled and grated
- 1 1/2 c. thinly sliced red cabbage
- 4 thinly sliced scallions
- 1/4 c. raisins
- 2 T. sesame seeds

### **Dressing:**

- 1 T. apple cider vinegar
- 2 1/2 T. mayonnaise
- 1 T. dried basil
- 1 tsp. garlic powder
- Dash of cayenne pepper

### **Instructions:**

1. In a large bowl, place broccoli florets, grated carrots, sliced cabbage, sliced scallions, raisins and sesame seeds. Toss to combine well.
2. In small bowl or measuring cup, combine apple cider vinegar, lite mayo, basil, garlic powder and cayenne pepper. Stir and pour over vegetables in large bowl.
3. Toss to allow dressing to cover vegetables.
4. Refrigerate 30 minutes to allow flavors to mingle and then toss well again before serving.

### **Nutrition Facts (Per Serving):**

Calories: 58  
 Sodium: 48 mg  
 Potassium: 295 mg  
 Phosphorus: 66 mg  
 Protein: 2 g



## Peach Cobbler

This recipe was submitted by Billy E. Paris for the  
**DCI Kidney Cookbook**

Prep time: 10 min  
Cook time: 30 min  
Total time: 40 min

### **Ingredients**

*Makes 6 servings*

- 1/2 c. all-purpose flour
- 1/2 c. sugar
- 1/2 c. milk, can sub unenriched milk alternatives like almond or rice • milk beverages for lower phosphorus
- 1 tsp. baking powder
- 2 c. sliced peaches (use juice also)

### **Instructions**

1. Mix together plain flour, sugar and baking powder
2. Add milk and mix
3. Add peaches with juice. Mix
4. Pour into a baking dish
5. Bake at 350°F until thick and brown on top

### **Nutrition Facts (Per Serving)**

Calories: 143  
Potassium: 156 mg  
Sodium: 97 mg  
Phosphorus: 52 mg  
Protein: 2 g

# DPC Raises Alarm on Health Workforce Shortages

department visit times have risen to 160 minutes, up from 143 minutes in 2020, according to government statistics.

Medicare beneficiaries who are intermittent users of health care facilities will probably not know when care is not timely or delivered to standards. But patients with ESRD, who visit their dialysis facilities 3 times per week over many years, are likely to recognize when something is amiss. Dialysis Patient Citizens surveyed members in 2023 about their experiences. We found:

62% of patients reported that the recent labor shortages had impacted their care: 43% said that staff turnover disrupted their care; 28% reported delays to their treatment; and 7% reported that they had to change shifts or facilities.

In 2013, in response to a question about wait times at facilities, the same proportion of patients, 14%, reported



**By Jackson Williams,**  
DPC Vice President of Public Policy

Fifteen years ago, the Institute of Medicine report, "Retooling for an Aging America: Building the Health Care Workforce," warned of looming health workforce shortages due to demographic changes. Has the era foreseen by that report arrived? Media reports indicate numerous instances of hospitals declaring "contingency standards of care" or ordering ambulance diversions due to staffing shortages. Average emergency

increases in wait times as decreases in wait times. This year, 24% report increases in wait times and only 11% reported decreases.

In 2013, we asked patients whether “in the past year, has time spent with health care providers (nurses, technicians) in your primary dialysis center increased, decreased, or stayed the same.” Ten years ago, only 13% reported the time had decreased; this year it was 26%.

This year’s Medicare payment rule only increased reimbursements to dialysis clinics by 1.7%, despite labor costs that have risen by 9.7% over the past two years. Complicating matters further, calculation errors the past two annual cycles have left payments 4 percentage points below what they should be. This makes it harder for dialysis facilities to hire staff. Hospitals that depend on Medicare are in the same boat.

The situation is not expected to improve, as the pool of workers available for health care jobs is shrinking. Over the next decade, the number of people of working age in the United States will increase by only 3 million (~1%) while the 65-and-over population will rise by 17.5 million (30%), according to World Bank projections.

With the trend toward work-from-home, jobs that are challenging and require in-person performance at fixed hours in the workplace will likely require a premium in salary over those that do not require commuting.

It is not clear if Medicare’s traditional price-setting processes are agile enough to adapt to labor scarcity. For both hospitals and dialysis clinics, payments are lagging changes in the labor market.

Policymakers must also begin to consider the impact that income inequality will have on health workforce and health care access.

As one expert has noted, disparities in buying power can divert essential resources from the poor [as] the well-off bid away resources and opportunities from the poor. Examples where this is already taking place include “concierge” medical practices and physicians concentrating on cosmetic procedures.

Currently, 69% of the wealth in the United States belongs to just 10% of the population. The lowest 50% of households own just 2.4% of total wealth.

If providers reliant on Medicare reimbursements can’t compete with employers able to draw revenue from that 10% of the population holding most of the wealth, manpower could migrate to work with less social utility, or a parallel health care system could emerge to serve the well-off.

DPC will continue to raise these issues with policymakers.





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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.



Join the call: Dial: 866-230-9002

Enter Meeting Code: 420 835 078#

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