issue number 14

The Kidney Citizen

A publication of Dialysis Patient Citizens (DPC) Education Center

DPC EDUCATION CENTER

Better Late than Never

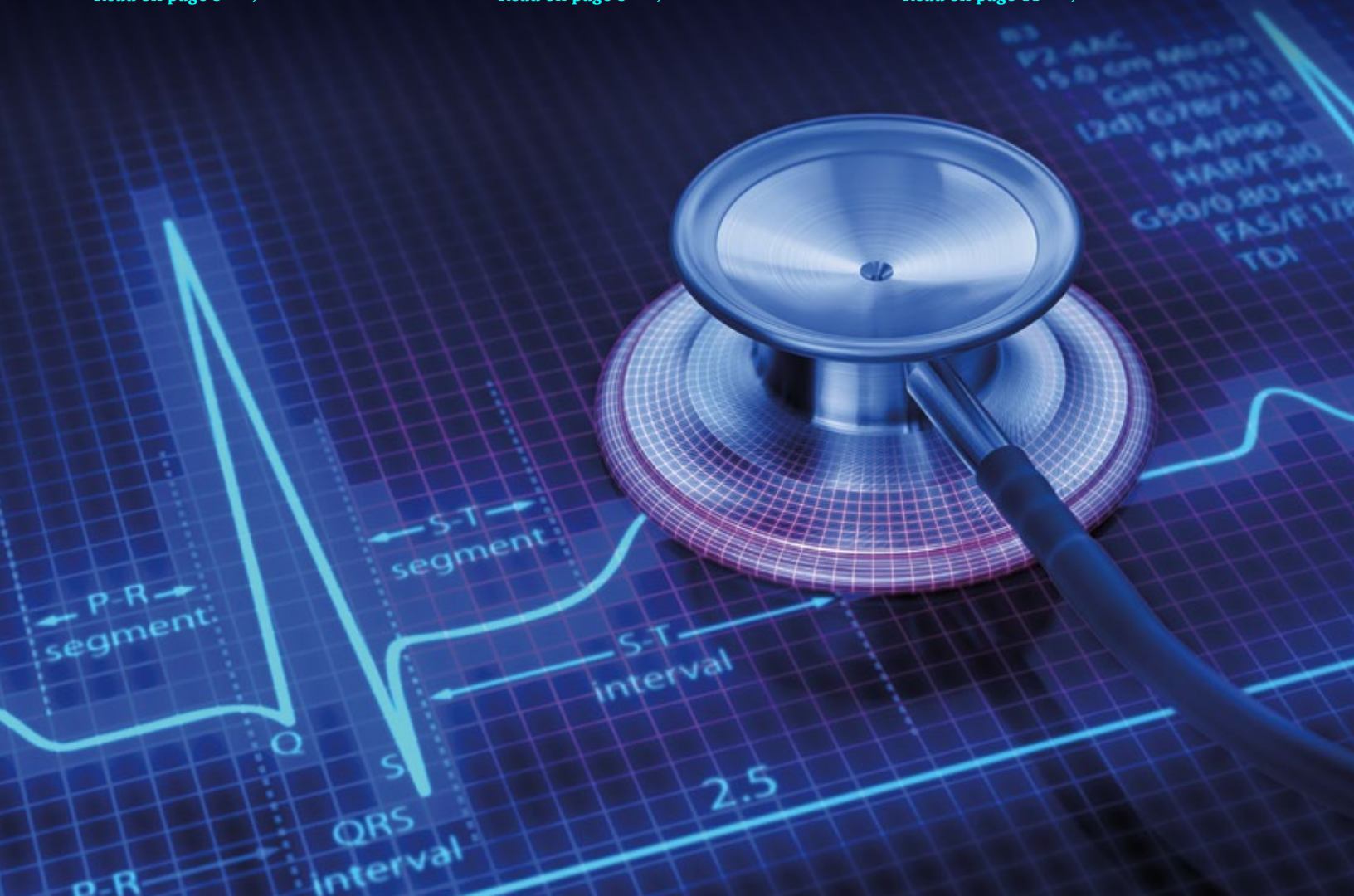
Read on page 3

Chronic Kidney Disease and Hyperkalemia

Read on page 8

DPC's New Report Card on Medigap Coverage

Read on page 11



President's Message

Hello DPC community and extended family,

We want to welcome our new members and hope to reach out to those who need the great information we must share. We want to empower our patients, their care takers, and families with the tools they need to survive in the times we are living in. I am very excited about this issue with the wonderful topics we have for you. We at DPC strive to educate you and to raise topics for great discussion amongst the CKD community. We want you to share with everyone your stories because we must raise the awareness of kidney disease to also prevent others from walking the same path.

Since my diagnosis of chronic kidney disease, leading into End Stage Renal Disease (ESRD), and now living as a transplant patient, I have become more and more curious to know what other diseases and illness caused other patients' kidneys to fail. In my research, I have come to realize that many other factors can attack one's kidneys. Most of our CKD population is aware that the two leading causes of kidney failure, are diabetes and high blood pressure; however, there are many other ways one's kidneys can fail and find themselves ending up on dialysis. There are conditions and illnesses that can attack the kidneys over time and there are many people who have inherited kidney disease.

In this issue, we will discuss diseases and conditions such as Fabry Disease, Hyperkalemia, and Polycystic Kidney Disease (PKD). Fabry disease is a rare disorder when the body lacks an important enzyme called alpha-galactosidase A. Over time, this can lead to life-threatening problems, including kidney failure. Hyperkalemia happens when potassium levels in your blood are higher than normal. It becomes harmful when it reaches high levels in the body where it causes serious heart and kidney problems. Those of us who have been on or currently are on dialysis know the day-to-day struggle of staying on a dialysis friendly diet in order to maintain the proper potassium levels. It is very important for ESRD patients to stay on top of that so that we can protect our heart. PKD is a genetic disorder that causes many fluid-filled cysts to grow in your kidneys, changing the shape of your kidneys and causing the decline in kidney function. PKD is a disease that touches my heart because I recently lost my mother earlier this year to cancer. She suffered from PKD in the later years of her life. It broke my heart to tell her that she would have to start dialysis in order to continue to live at the age of 78. It was most difficult because she watched me go on dialysis and therefore understood the pain, emotional toll, and difficulty that came along with living on dialysis. What helped was she also witnessed the courage and will I had to live being on dialysis at a young age and making sure kidney disease did not beat me. I remember the countless stays in the hospitals and scares my family and I endured when these cysts would burst internally, and my mother would be in so much pain. She experienced such discomfort as her kidneys would press up on other organs in the abdomen area. These are a few of the other diseases we will discuss to better understand.

I remember when I was on dialysis and wondering if I would be able to continue traveling. I remember the great joy I felt to learn about all the traveling opportunities afforded to ESRD patients such as being able to receive dialysis at other dialysis facilities and cruises that provide dialysis on their ships. Please take advantage of the information as we help you navigate your next road trip, flight, or cruise line whether you are an in-center patient or a home dialysis patient.

We at DPC want to thank our former DPC Education Center president, Nancy Scott, for starting our support group. I would like to encourage you to join our support group. Nancy has prepared wonderful topics and has brought in experts to help navigate and educate our community on topics that need to be discussed. When I was on dialysis and now as a transplant recipient, I feel it is very important to be a part of a group and a community of individuals that have similar experiences and pertinent questions that benefit all of us. I enjoy being a part of the support group and what we discuss is vital to our wellbeing and our emotional state. I look forward to hearing feedback and receiving more topics of interest from our wonderful CKD community and family.

Stay safe and well wishes,

Merida Bourjolly

DPC Education Center Board President

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Better Late than Never: Genetic Diagnosis After Major Medical Events

By Dawn Laney, MS

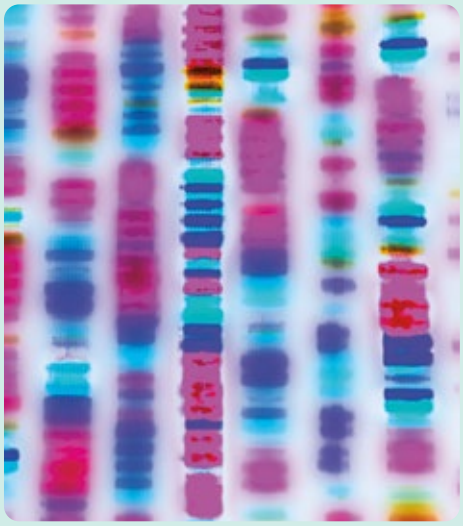
You have two doctors for your kidneys, one for your heart, one for your head, one for your eyes, and one for your overall health. You are tested, biopsied, and imaged from head to toe on a regular basis. So, when one of these doctors suggests a referral to genetics, you may wonder, "Another doctor? Is it still worth seeking a genetic diagnosis as an adult who has already had kidney failure?" The answer is a resounding "Yes!" One way to improve care in a medically complicated situation is by learning if an underlying genetic condition could be playing a role in major medical event like early kidney disease. A diagnosis provides a window into potential future medical events and allows your medical care team to most effectively address current concerns, while also developing a plan to catch and treat future symptoms early.

Let's take a specific example. Sometimes, kidney biopsies find that someone has lipid storage "consistent with Fabry disease" and suggest further evaluation. The next step would be looking for other medical history clues that an individual has Fabry disease and performing a simple blood test to confirm or rule out that condition. Why does it matter if someone has Fabry disease? There are 3 major reasons.

Reason 1. Predicting the Future: Fabry disease is a progressive X-linked genetic condition that ranges in symptoms from a childhood onset "classic" form across the spectrum to a later onset, but still life impacting, "nonclassic" form. In Classic Fabry disease, the initial symptoms begin sneakily with nonspecific complaints such as lack of sweating leading to problems

with overheating, severe belly pain and diarrhea that looks like irritable bowel syndrome, chronic fatigue, a "whorl" in the cornea that can be seen on slit-lamp exam and burning pain in the hands and feet. Over the next 20-30 years those health issues continue and are joined by chronic kidney disease, hearing loss, heart rhythm changes, enlargement of the heart, and a host of other symptoms. Patients with nonclassic disease can experience all or some of these symptoms, but usually they do not begin in childhood. Sometimes nonclassic Fabry disease will be focused on a major organ and cause onset of progressive heart disease beginning in the 30s or 40s. Other times, nonclassic Fabry disease results in kidney failure in the 50s or 60s, with heart disease not far behind. In any of these cases, the key to a good quality of life and decreasing the risk for major events in adults living with Fabry disease is having a medical team focused on treating cardiac disease and working to prevent strokes. If someone is affected with Fabry disease, but doesn't have the diagnosis, they may not be receiving the best monitoring and treatment.

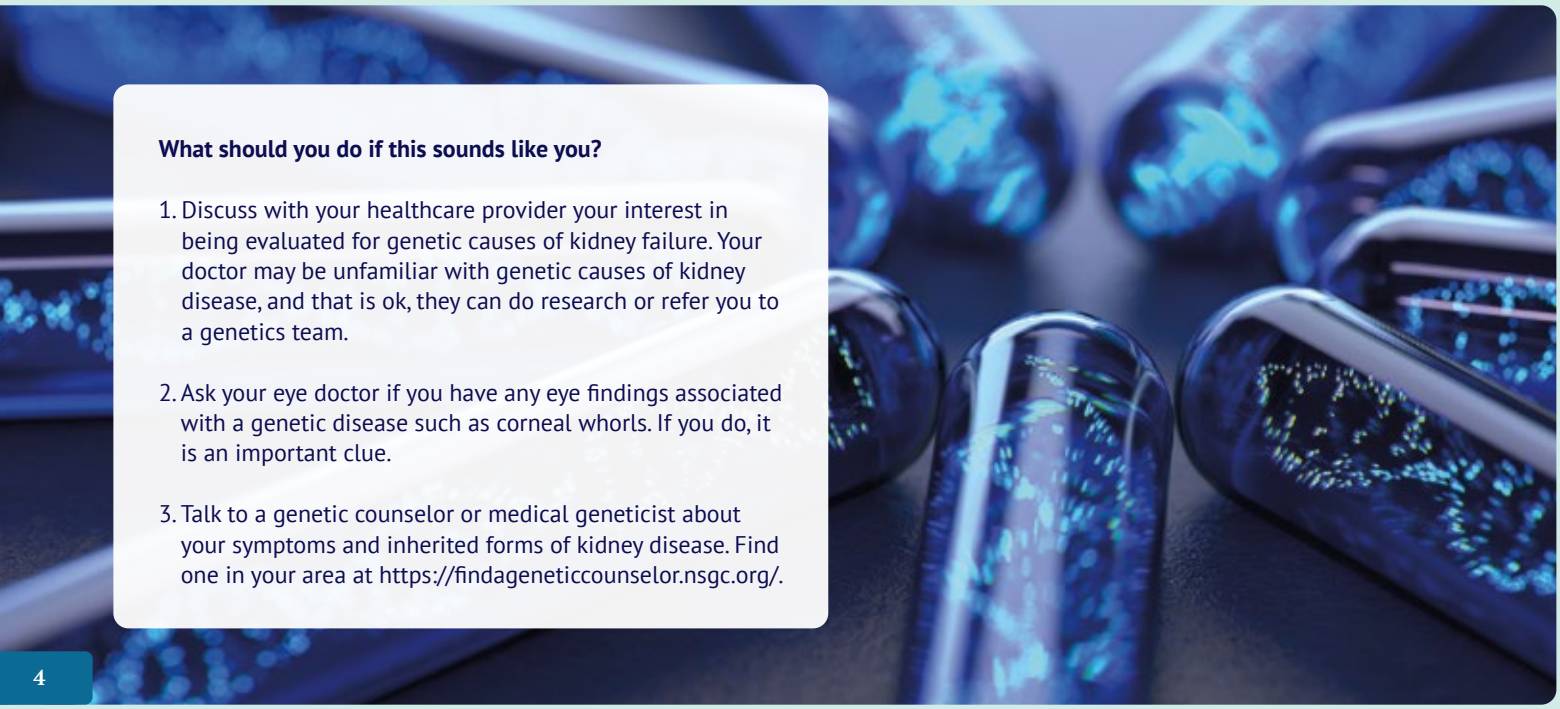
Reason Number 2: Targeted therapy: There are two United States Food and Drug Association (FDA) approved medications that address the root cause of Fabry disease: agalsidase beta (Fabrazyme ®, Sanofi-Genzyme) and migalastat (Galafold ®, Amicus Therapeutics). In all cases, treatment is most effective when



begun as early as possible. This means that diagnosing a genetic disease reduces the time to beginning the best, most effective treatment and leading to the best outcomes.

Reason Number 3: Your Family. When someone is diagnosed with a genetic condition, it has implications for their family members. After a diagnosis, doctors should take a detailed family history to find out if other family members might have or will be affected by some or all of these health issues. If these clues suggest the condition, testing of blood or saliva is the next key step. Treatment can begin earlier which leads to better outcomes. Medical geneticists and genetic counselors are health care providers who are specially trained to take family histories, identify at-risk family members, seek out clues to underlying genetic conditions, organize genetic testing, interpret genetic testing results, and discuss therapeutic options, including clinical trials. Could any doctor order the testing? Sure! But in genetics the "what next" is often just as important as the testing.

Fabry disease is just one example, but it embodies the importance of investigating the underlying causes of early renal failure, particularly if many people in a family have had earlier onset proteinuria or kidney disease. If kidney disease runs in a family, begins in 40s or 50s (without diabetes), or happens in combination with symptoms such as early hearing loss or burning pain it may be worth talking with a healthcare provider about possible genetic causes of renal disease. A genetic consult and testing can help determine if there is an underlying genetic cause for kidney problems and who else in the family might be at risk. Identifying a genetic cause can then open the door for targeted treatment that is most effective and help other family members receive early treatment. All of these can improve the quality and quantity of life for patients, and that's the whole point. You can learn more about genetic causes of kidney disease at: https://www.uclahealth.org/core-kidney/genetics-and-ckd or by viewing Genetic causes of Renal Failure video at https://www.dpcedcenter.org/what-is-kidney-disease/what-causes-kidney-disease/.



What should you do if this sounds like you?

1. Discuss with your healthcare provider your interest in being evaluated for genetic causes of kidney failure. Your doctor may be unfamiliar with genetic causes of kidney disease, and that is ok, they can do research or refer you to a genetics team.

2. Ask your eye doctor if you have any eye findings associated with a genetic disease such as corneal whorls. If you do, it is an important clue.

3. Talk to a genetic counselor or medical geneticist about your symptoms and inherited forms of kidney disease. Find one in your area at https://findageneticcounselor.nsgc.org/.

Greetings from San Antonio, Texas

By Natalie Zuniga,
DPC Board Member

My name is Natalie Zuniga and I survived the 2021 Texas ice storm with my spouse, Eddie Zuniga, who is also a dialysis patient!

I have been a dialysis patient for over three years and my husband has been a dialysis patient for eight years. At first, we thought it was a death sentence and we were not going to live much longer, and we gave up. But then, by hard work and education through Dialysis Patient Citizens and our nutritionist, Mary, we are now thriving and enjoying life as seniors. We also are looking forward to bettering our lives with future kidney transplants.

We had a week that challenged us though, with a weather emergency that will go down in history. We live in Texas and the Texas ice storm in February 2021 was a freak occurrence. The last time it even snowed was in 1985, so we were not prepared for this major event.

On Monday, day one of the storm, my husband and I went slowly to our dialysis center while slipping and sliding; however, we made it there safely! Our medical team at DaVita Las Palmas were so dedicated that they all showed up. One tech said that he left his house at 2 am to make sure he made it by 5 am. Wow, that's dedication. They explained to us that we were only going to get two hours of treatment compared to our normal four hours. They also requested us to follow the renal diet and to monitor our water intake from 32 oz to just 16 oz because they did not know when our next treatment would be.

When we arrived back at our home, the electricity and water were no longer working. We live in a tiny home and have three fur babies, two of which prefer to sleep in their doghouse outside. I would let them out occasionally even though they were upset because they wanted to be outside, and the temperature was extremely cold. We snuggled in our comforters and my husband had a small generator to charge our phones. I could not turn on my CPAP machine, which helps me get a good night's sleep, and I felt exhausted most of the time.

We melted snow for our toilet use and our sponge baths. Our electricity was on periodically, but we would not get a heads up when it would go down. We did not eat salty meals or snacks to avoid getting thirsty. We did not open the refrigerator door to try to save our perishables. Since the renal diet works on lean meats and fresh vegetables, we filled our ice chest with snow to save our meats. But mainly we ate canned tuna and turkey, which would not spoil.

On that Wednesday, we again showed up at our dialysis center for treatment. They started dialysis, but within 15 minutes, the facility lost water. The staff director explained that due to the lack of water they were not be able to continue our treatment. The only option was to go to the hospital if you felt bad. However, the hospitals were declining any patients unless it was a life-or-death situation due to the pandemic.

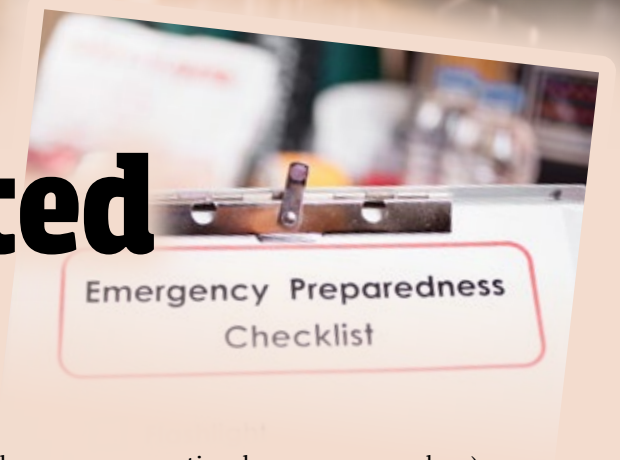
On Thursday, I could not take it any longer and we made a reservation at one of the only hotels that had electricity and water. I was able to shower and use my CPAP machine. I felt like a new person even though I had to continue to minimize my fluid intake.

Friday finally came and we received our full treatment. We still did not have water at home, even though my husband had made sure the pipes were covered. We attempted to go shopping for water, bread, and anything fresh but the grocery store was empty. We have a 5-gallon dispenser of water, and it was enough for the six days, so we still could manage the water situation.

There were lessons to be learned from this weather emergency. I learned that in order to be prepared for emergencies, it is important to always have water stored and to make sure you have a measuring cup to monitor your personal water intake. Also, have non-perishable renal friendly foods and make sure you take your medication as prescribed.

My spouse and I are extremely grateful that we survived as some of my fellow dialysis patients were not so lucky. We are extremely grateful for our Las Palmas DaVita team and for DPC providing webinars, which are recorded and can be watched at any time (*www.dpcedcenter.org*).

Be Ready for Weather-Related Emergencies!



By Mike Guffey,
DPC Board Member

It is critically important for dialysis patients to be prepared for weather emergencies, especially as we head into the hurricane and winter weather seasons. Patients should have an emergency checklist and a "go" kit with emergency supplies. www.ready.gov is a good go-to site with checklists and contact cards to help your family be prepared. You should gather the information well in advance of any incidents, but it is helpful to review them at the start of each severe weather season.

Maintain the kit in a sturdy plastic container and rotate supplies on a regular basis.

Do not wait until the emergency occurs as some items may not be easily acquired or gathered in those situations. Additionally, if you have children, it is important to rehearse your plans so they remember what they need to do in the excitement, especially if they get separated.

For dialysis patients, the kit should include:

- 3-day supply of water
- 3-day supply of shelf-sustainable renal diet-friendly foods and manual can opener
- Disposable utensils and plates/bowls
- Eyeglasses and face masks
- Ample supply of medications, including OTC and medicines and diabetic supplies (should be added last minute)
- First aid kit
- Flashlight/lantern and battery-powered/hand-cranked radio
- Copies of important family documents, including insurance information and numbers below.
- Paper and pen/pencil
- Cell phone charger

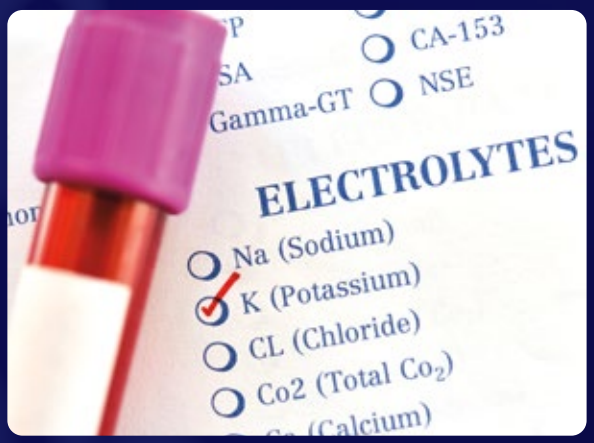
Phone numbers to have at hand:

- Dialysis provider (home clinic and national emergency numbers)
- Nephrologist and other primary doctors
- Pharmacy (and list of current medications, including dosage and frequency).
- Local contact number(s)
- Key distant family contact

Some other key items to think about:

- If possible, have emergency cash or traveler's checks on hand, as merchants may have lost power and be unable to accept cards.
- If evacuating your residence, turn off applicable utilities such as water and gas at the main feed. Turning off gas and water, in particular, will prevent water or gas leaks inside.
- If you are relocating, contact your dialysis unit to let them know and make alternative arrangements, as needed.
- Try to stay calm and remain composed. Your attitude can affect those around you, especially children.

Chronic Kidney Disease and Hyperkalemia: What You Need to Know About High Potassium!



By Sue Hellie

The challenges faced this past year have redefined what it means to live with chronic kidney disease (CKD). People living with kidney disease and other severe chronic conditions are at higher risk for more severe illness, and they've had to take extra precautions to ensure their safety and wellbeing. However, this past year has presented many people with the opportunity to educate themselves about their health and potential associated conditions that come with living with CKD.

One condition that is less understood by many living with CKD is hyperkalemia.

What is hyperkalemia?

Hyperkalemia is a condition some people with CKD face that is characterized by elevated potassium levels in the blood. In 2014, an estimated 3.7M US adults were affected by this condition and it impacts up to 40-50% of treated patients with CKD. Hyperkalemia can potentially be life-threatening if left untreated.

How do you know if you have hyperkalemia?

Many people do not experience symptoms and have been surprised with a diagnosis after undergoing routine blood work. For those who are on dialysis—which can help to lower potassium levels during treatment— it's important to consult with a doctor to check potassium levels on a regular basis, as it can increase between sessions. This increase may result in serious health issues, including weakness, nausea, potentially irregular heartbeats, and paralysis.

How can you manage hyperkalemia?

With the many challenges faced by people living with CKD, it's critical to ensure everyone has access to the essential tools and resources to allow the opportunity to live fuller and healthier lives. To help better manage CKD and your potassium level, here are three easy steps you can take in order to learn more about hyperkalemia:

1. Talk With Your Doctor:

Talking to a doctor is often a helpful first step to discover how to manage potassium levels and feel more in control. If you are currently on medication, ask your doctor about which medications could be impacting your potassium levels and if medication is needed to help lower or manage your potassium level. Through frequent, unfiltered conversations, you can learn better management of your CKD and help your support system discover how to help you on your CKD journey.

During your next conversation with your doctor, bring a CKD discussion guide (see Additional Resources below) that includes specific questions to ask about hyperkalemia and help you better understand this condition.

2 .Know Your Options:

A great first step to understand which food choices and other healthy habits will help you to feel your best is to speak with your doctor. To supplement that conversation, here are some helpful resources:

- **Beyond Bananas** campaign offers nutritional tools and more information about high potassium
- The **Are You OK+** campaign provides digestible resources to help people understand their potassium level and make healthy lifestyle choices

3. Find Resources & Your Fellow Warriors:

CKD is a complex disease to navigate. Through education, we can empower those impacted by this disease to seek treatment, restore a sense of self-control and work towards potentially lowering the risk of high potassium-related events. Not only is it important to continue learning about CKD's associated conditions, like hyperkalemia, but also join a group that is navigating the same waters as you – as the saying goes, there is strength in numbers.

The Unfiltered Kidney Conversations Facebook community creates a transparent space for people living with CKD – CKD warriors – to share their story and offers numerous tools and resources to have a candid dialogue about this disease. Learn more about this community by checking out their Facebook page referenced below in Additional Resources.

While managing your kidney health can be complicated, there are numerous ways to feel empowered and learn the ins and outs of your kidneys and this condition. Not only is it important to educate yourself on your own kidneys, but spreading the word about the potentially serious effects of high potassium could help other people address this issue. Together, we can support others and work towards a better, brighter future in potassium management for millions of CKD warriors.

Additional Resources:
Visit these pages for materials to support your CKD journey
Chronic Kidney Disease Doctor Discussion Guide: https://www.unfilteredkidneyconvos.com/
Unfiltered Kidney Conversations Facebook Community: https://www.facebook.com/UnfilteredKidneyConversations
Beyond Bananas: https://kitchen.kidneyfund.org/potassium/
Are You OK+: https://aakp.org/center-for-patient-research-and-education/hyperkalemia/

DPC Support Group

By Nancy Scott

Why should I attend a renal support group? Why not? DPC has started a support group for people who have renal disease, family members, friends—essentially anybody who needs support and wants to give support. The journey of dialysis and transplantation can be fearful, depressing, tedious and tiring. This support group addresses these types of issues and more. No one should have to deal with these issues alone and a support group is a reliable, dependable, caring, and safe place to discuss concerns that may arise along the way.

You are cordially invited! The support group meets every second Tuesday via telephone at 3:00 pm (EST). The telephone number is (866) 808-5953. The meeting code is 253 841-3353. The meeting is moderated by a patient and always joined by DPC staff members. A guest is always invited who has expertise in nephrology, transplantation, nutrition, psychology, and much more. Call in and let us support each other!

DPC's New Report Card on Medigap Coverage Helps ESRD Patients Understand their Medicare Supplemental Insurance Options

By Kelly Goss, J.D., LL.M.,
Western Region Advocacy Director

If you're a dialysis patient under age 65 looking to purchase a Medigap plan, DPC's new interactive Medigap Report Card will help you understand the availability of Medigap coverage in your state.

Medicare Supplemental Insurance, or Medigap, is provided by private insurance companies to help Medicare enrollees cover their out-of-pocket "gap" costs – such as copays, coinsurance, and deductibles – not covered by Original Medicare. Providing accessible and affordable Medigap coverage is critical to ensuring patients with End Stage Renal Disease (ESRD) can fully cover the cost of their care, since Medicare alone only pays for 80 percent of an individual's health care costs. Medigap coverage not only offers dialysis patients greater financial security and stability, but also increases access to kidney transplants since secondary coverage is almost always needed to cover the cost of a transplant, ongoing medical care, and immunosuppressant drugs.

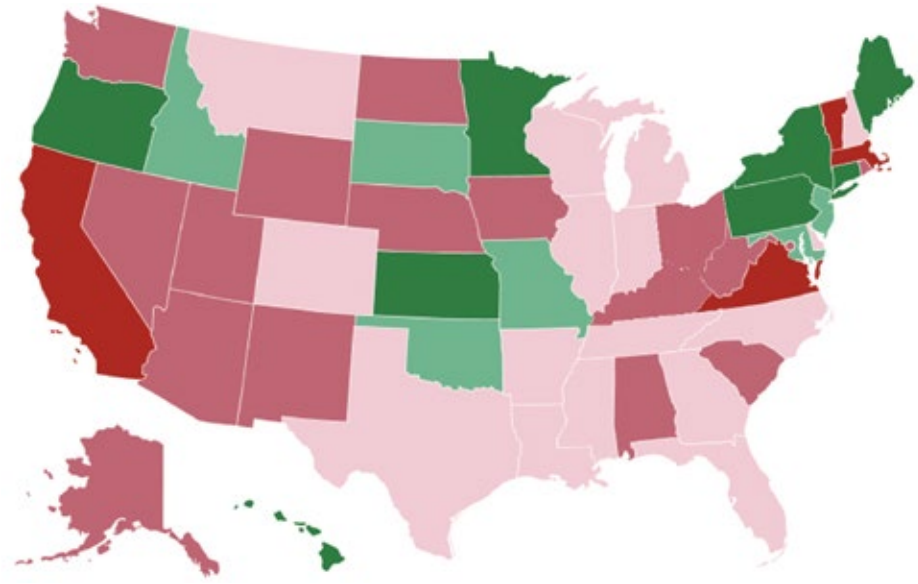
While federal law requires insurers to offer Medigap coverage to Medicare enrollees upon turning age 65, that protection does not extend to individuals under age 65 who are Medicare enrollees due to a diagnosis of ESRD or qualifying disability. Rather, individual states determine Medigap insurer requirements for patients under age 65, resulting in varying rules and fragmented coverage across the country.

As the Medigap Report Card map (below) highlights, of the 30 states (states with grades A, B and C) that require insurers to offer some degree of Medigap coverage to those under age 65, fewer than half require affordable premiums. Worse, 20 states and the District of Columbia (those with grades D and F) do not require insurers to offer Medigap coverage to Medicare enrollees under age 65; if plans are available in these states, premium rates are significantly higher for those under age 65 since there is no state law to provide patients with premium protections. The inability for dialysis patients under age 65 to access affordable Medigap plans creates significant barriers and further exasperates health inequities.

To help address these disparities in Medigap access, DPC is advocating in support of legislative efforts, at both the state and federal level, to provide all ESRD patients with access to affordable supplemental insurance, which would lead to improved health outcomes and lower health costs.

In summary, DPC's Medigap Report Card provides patients and policy makers with an interactive map to check the availability and affordability of Medigap coverage in each state in order to learn what, if any, protections currently exist. Using this information, patients can then work directly with lawmakers to secure patient protections and improve access to affordable Medigap plans.

Visit DPC's Report Card on Medigap Coverage: **https://www.dialysispatients.org/medigap.**



- State requires all/most plans to be offered and affordable to ESRD patients under 65
- State requires some plans to be offered and affordable to ESRD patients under 65.
- State requires some plans to be offered, but they are not affordable to most ESRD patients under 65.
- State does not require coverage. Some plans are offered, but they are not affordable to most ESRD patients under 65.
- State excludes coverage. Some plans may be offered, but they are not affordable to most ESRD patients under 65.

Research Report Finds Minimal costs to enacting Jack Reynolds Memorial Medigap Expansion Act

By Jackson Williams,
DPC Vice President of Public Policy

A research report commissioned by DPC has found that passage of the Jack Reynolds Memorial Medigap Expansion Act (H.R. 1676) would add only minimal costs to the federal treasury and to seniors' Medigap premiums. H.R. 1676 would require insurers to make Medigap plans available to End-Stage Renal Disease (ESRD) patients under the age of 65. The report from Health Management Associates (HMA) calculated the costs associated with changing the law.

Under current federal law, insurers are not required to offer Medicare Supplemental Insurance (also called Medigap) plans to patients under 65 years of age. While Medicare pays for roughly 80 percent of an individual's healthcare costs, patients are required to cover the remaining 20 percent out-of-pocket. Medicare beneficiaries who live in states without added patient protections for individuals under the age of 65 often struggle to cover their health care costs. The lack of supplemental insurance also remains a significant barrier for many dialysis patients trying to secure a kidney transplant, as they are often required to demonstrate they possess the remaining funds to cover a potentially life-saving transplant surgery in order to remain "active" on the transplant waiting list.

Health policy experts often criticize Medigap's relief from cost sharing as adding to Medicare expenditures. However, using Medicare cost data from 2017-2019, HMA estimated that extending Medigap coverage to all ESRD patients under the age of 65 would only add about $50 million in federal expenditures over the next 10 years. HMA actuaries compared the utilization of services by dual eligible dialysis patients vs. Medicare-only dialysis beneficiaries, and found that the one relevant increase in cost was in drug spend. HMA suspects that by expanding access to Medigap coverage, more dialysis patients will have the money to pay for all of their prescribed medications, as their supplemental insurance would now cover their other health care related expenses. Therefore, HMA projected a de minimis cost increase to Medicare due to increased utilization under Part D following the expansion of Medigap access to patients under 65 years of age. This finding gives momentum to H.R. 1676, as Congress often shies away from changes to law that significantly increase expenditures.

The HMA report also found that in the majority of states where most ESRD patients are affected, where under-65 access to Medigap is limited or unaffordable, guaranteeing equal access to affordable plans would increase premiums by less than one percent.

DPC is calling on Congress to enact the Jack Reynolds Memorial Medigap Expansion Act, which was introduced earlier this year by Representatives Cindy Axne (D-IA) and Jaime Herrera Beutler (R-WA), to help provide ESRD patients with the supplemental insurance they need to remain financially secure. DPC recently released an interactive State Report Card on Medigap Access and Affordability for ESRD patients under 65 available at: www.DialysisPatients.org/Medigap

H.R. 1676 The Jack Reynolds Memorial Medigap Expansion Act

By Megan Hashbarger,
Vice President of Government Relations

Earlier this year, The Jack Reynolds Memorial Medigap Expansion Act (H.R. 1676) was reintroduced by Congresswoman Cynthia Axne (D-IA-03) to ensure all End Stage Renal Disease (ESRD) patients have access to Medigap. This Congress, we were very pleased she was joined by Congresswoman Jaime Herrera Beutler (R-WA-03) in leading this effort. Ensuring all ESRD patients have access to Medigap is extremely important to help patients cover the high costs of care and to improve their access to transplantation.

Medigap policies are standardized, private insurance policies that cover costs not covered by Medicare, such as copayments and deductibles. Current federal law does not specify that all Medicare beneficiaries, specifically those under the age of 65 such as many dialysis patients, have access to Medigap to cover their substantial out-of-pocket costs. However, it does guarantee that those over 65 have access to Medigap. Because of this uncertainty, some states allow patients under 65 access to Medigap while others do not, leaving dialysis patients being treated differently based on where they live.

This is not only an issue because access to Medigap will help patients improve their financial security, it is also an issue because Medigap will improve access to transplantation. Without Medigap, many patients do not have the 20% coinsurance payment needed in order to receive a transplant. Unfortunately, in 2019, (prior to the ongoing pandemic) 5,207 patients were removed from the transplant list for reasons of death. Access to Medigap and thus transplantation could have saved many of these lives.

While making this fix seems commonsense, in the past, some health policy professionals, have had concerns this could be a significant cost to Medicare. However, Health Management Associates recently released a report using Medicare cost data from 2017-2019 that estimated extending Medigap coverage to all ESRD patients under the age of 65 would only add about $50 million in federal expenditures over the next 10 years. Now, this really is commonsense.

Jack Reynolds knew just how important access to Medigap was. He was the longest surviving dialysis patient in the U.S. (45 years) and often talked about how fortunate he was to have a Medigap plan to help cover his health care costs. Jack was also our long-time Board President and passionate advocate on improving the lives of dialysis patients. H.R. 1676 – The Jack Reynolds Memorial Medigap Expansion Act is a wonderful tribute to Jack's memory as it would do what he was most passionate about – improve the lives of dialysis patients. We hope Congress will take swift action to pass this important legislation.

Please contact your Member of Congress and ask him/her to join Reps. Axne and Herrera Beutler by taking action by taking action at **www.kidneyaction.org.**

Kidneys: Holy Grail Pursuit of Regenerative Medicine

By Anthony Atala, MD,
Director, Wake Forest Institute
for Regenerative Medicine

Recently, two teams of scientists from the Wake Forest Institute for Regenerative Medicine (WFIRM) won first and second place in NASA's Vascular Tissue Challenge, a prize competition that aims to accelerate tissue-engineering innovations.

Vascularization of engineered solid organs – like the kidney – is part of the Holy Grail pursuit of regenerative medicine. Being able to create organs with the needed blood vessel structure means the organs are supplied with needed nutrients and oxygen to survive when implanted.

The two Wake Forest teams both used 3D bioprinting technology to create liver tissue constructs that were vascularized and able to mimic the human liver function in the body and survive for 30 days in the lab. Each team used different 3D-printed designs and different materials to produce live tissues that harbored cell types found in human livers and mimicked liver function in the body. The recent NASA news of the awards was exciting to share because what we learned through this research challenge helps to inform our work overall to succeed in the vascularization of solid organs.

As readers know all too well, there are simply not enough donor tissues and organs to meet demand. In the United States, chronic kidney disease is prevalent, affecting more than 700,000 patients living with end stage renal disease. Although dialysis has supported the survival of patients with end stage renal disease, kidney transplantation remains the only definitive treatment. However, there are currently nearly 100,000 people on the waiting list, with nearly 9,000 patients removed yearly due to deteriorating medical condition or death, which reflects the current state of ongoing organ shortage.

The limitations of current therapies for end stage renal disease led WFIRM researchers to explore the development of renal 3D constructs with the goal of improving, restoring, or replacing partial or total renal function. Regenerative

medicine, which aims to harness the body's innate healing abilities, offers the hope of engineering replacement organs in the lab to help solve this shortage. Because these organs are made with a patient's own cells, there will be no issues with rejection as there are with organs from donors.

While kidney transplantation is currently the most effective therapy for end stage renal disease, scientists around the world are looking for better options due to the shortage of donor organs and the side effects of immunosuppression. As a solid organ, the kidney is very dense with cells, which means that it has high requirements for oxygen. The intricate nature of the renal vasculature makes replication difficult. The challenges in engineering functional replacement kidneys are many, from growing the millions of cells required to engineer the organ to finding a way to supply the organ structure with oxygen until it can integrate with the body.

WFIRM scientists have created kidney scaffolds using biomaterials and cells that experimentally were shown to be functional, in that they were able to filter blood and produce dilute urine. This research is still underway and progressing. The teams are also working on other promising strategies – "recycling" discarded organs, cell therapy, and partial augmentation.

"Recycling" Discarded Organs

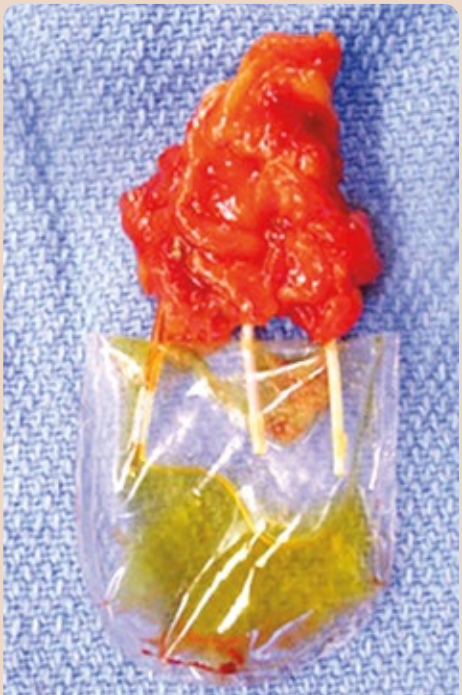
One strategy is to use discarded organs from humans as a platform for organ engineering. The process starts by removing all cells from the organ, leaving the "shell" of the organ to create a scaffold that could hold a patient's own cells. Crucial microvessels vital to filtering contaminants were left intact after the scrubbing process, while growth factors needed to maintain function were also retained. The patient's own cells can then be expanded and used to repopulate the scaffolds. About 2,600 donated kidneys are discarded each year after they are found to be unsuitable for a transplant. The team believes that this is a resource that can be salvaged with the right prep work.

Cell and Molecular Therapy

By harnessing the unique properties of human amnion-derived stem cells, WFIRM scientists have demonstrated that using therapeutic cells could potentially help recover organ function in a pre-clinical model of kidney disease. Our studies demonstrate that treatment with amniotic fluid stem cells had positive effects on functional improvement and structural recovery of the kidney. WFIRM scientists were first in the world to identify and characterize stem cells derived from amniotic fluid and the placenta in 2007 and have developed techniques for isolation and expansion of the cells. Amnion-derived stem cells can be used as a universal cell source because they have the ability to become different cell types as well as the ability to be anti-inflammatory, making them a potential source for regeneration. Unlike other stem cells, amnion-derived stem cells are not as likely to provoke an immune system response. Additionally, their use does not lead to risks of tumors, as with other stem cells.

WFIRM scientists also developed a system to isolate normal cells from kidneys. The cells can be obtained from end-stage failure kidneys. The cells can be expanded, grown outside the body, and can then be delivered in a gel solution into the same patient. This therapy is currently in clinical trials in order to prevent patients with diagnosed kidney failure from progressing to transplantation.

WFIRM has a team that is studying the effects of a cell-derived molecular therapy to treat kidney fibrosis. In this research, already tested in cats with chronic kidney fibrosis, scientists are using a cell-signaling chemokine – CXCL12 – that is produced by cells and stimulates tissue regeneration. They hope that what they learn will someday help inform treatment for humans.



Partial Augmentation Strategy

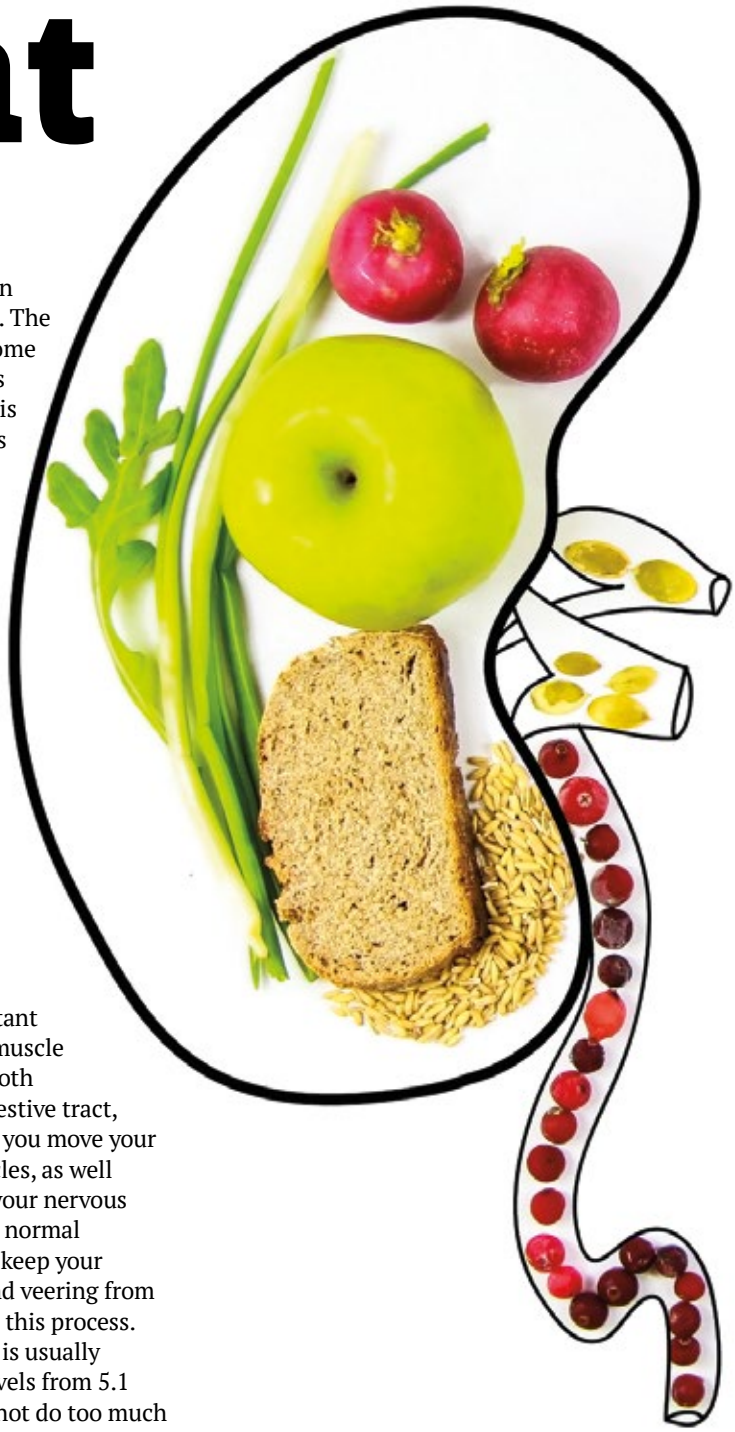
In a proof-of-concept study, WFIRM researchers showed the feasibility of bioengineering vascularized functional renal tissues for kidney regeneration, developing a partial augmentation strategy that may be a more feasible and practical approach than creating whole organs.

The scientists created a novel collagen-based vascular scaffold – a mold – that is structurally identical to a native kidney that was able to develop vascularized tissue.

The scientists essentially made molds using donor kidneys as templates, creating hollow scaffolds that were cultured before implantation into the preclinical model. The renal vascular scaffold showed a 3D branching architecture with visible hollow channels that were interconnected and continuous. These branching structures were able to allow perfusion similar to native blood vessels. The researchers showed that the vascular scaffolds integrated with the host vessels and supported renal cell viability. The results are promising and support continued exploration of this method to further evaluate the improvement of renal function. Overall, we are pleased with the outcomes thus far, but further work is necessary to establish a reliable and reproducible system for clinical translation.

In summary, while there are many challenges to meet for complex structures like the kidney, regenerative medicine therapies are starting to reach patients with end-stage renal failure. I think we can safely say that the timeframe for wide distribution of these therapies will be decades, rather than a few years, but science can surprise you.

Hyperkalemia From a Dietitian's Viewpoint



By Fanny Sung Whelan, MS, RDN

Have you been diagnosed with hyperkalemia?

Hyperkalemia refers to a medical condition that occurs when the potassium level in your blood gets too high [1]. "Hyper" means "over or beyond", and "-kalemia" means "the presence of potassium in the blood." Hyperkalemia is a common diagnosis, and luckily most people have mild cases that are well tolerated, but even mild cases need to be treated to prevent more serious cases from occurring. If left untreated and severe hyperkalemia develops, which is defined by blood potassium levels of 7 mEq/L or higher, cardiac arrest and death can occur [2]. Fortunately, there are treatment options to prevent this from happening.

What causes hyperkalemia?

Hyperkalemia is generally caused by reduced renal function, such as acute or chronic kidney failure, glomerulonephritis (when the glomeruli that filter the blood of waste products get injured), lupus nephritis, or any condition that involves blockages in the urinary tract, such as urolithiasis (when stones form in the urinary tract) [2]. Also, people who have reduced kidney function are generally more sensitive to potassium-containing ingredients and medications. Salt substitutes that contain potassium can add a significant amount of potassium to the body, and medications such as some that help to control blood pressure like ACE inhibitors and angiotensin receptor blockers (ARBS), NSAIDS like ibuprofen or naproxen, and diuretics that spare potassium, can add more potassium to the body than needed [2].

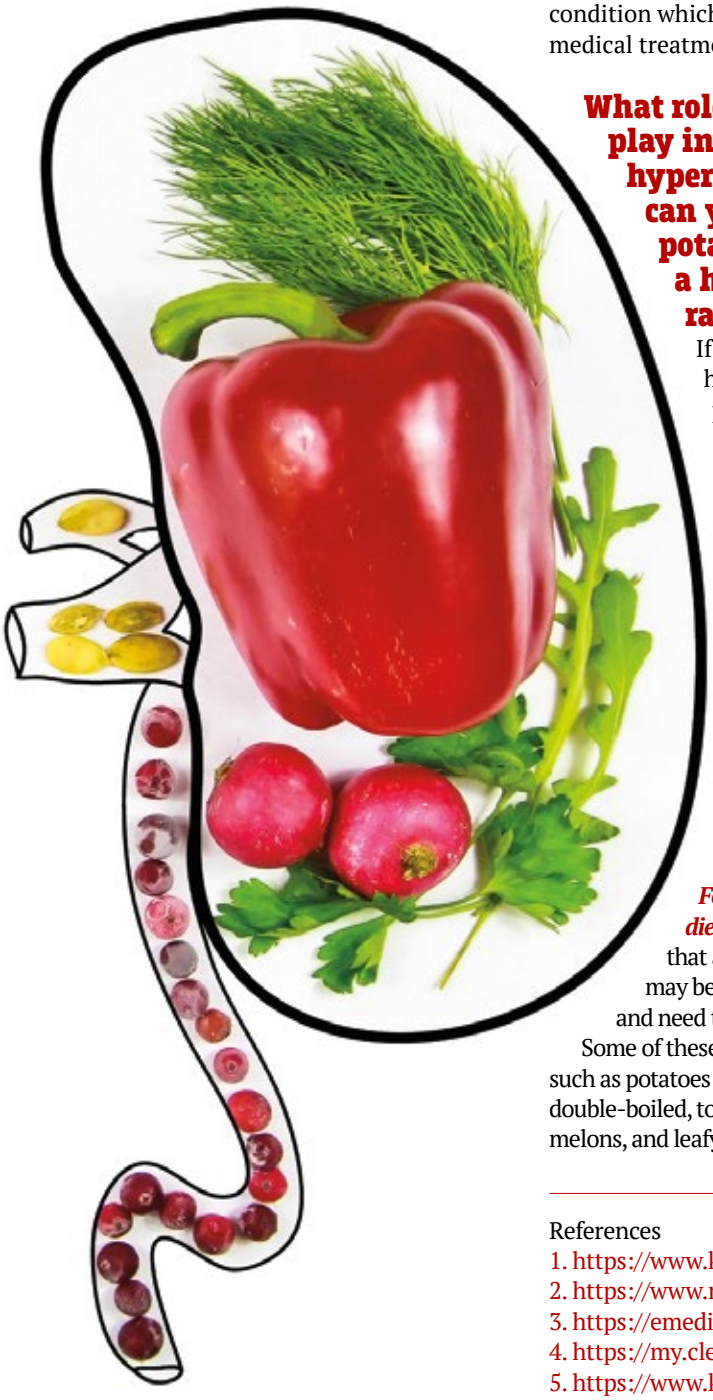
Adrenal gland diseases can also lead to hyperkalemia. The adrenal glands produce some hormones, one of which is aldosterone. Aldosterone is the hormone that controls sodium retention and excretion, as well as potassium removal in the urine. If these glands are diseased or injured, that can affect the production of this vital hormone that helps your body stay in its sodium-potassium equilibrium [2].

What happens to your body when hyperkalemia occurs?

Potassium plays a crucial role in a number of important bodily functions, such as muscle movement, including smooth muscles found in your digestive tract, skeletal muscles that help you move your body, and your heart muscles, as well as signal transmission in your nervous system. Most importantly, normal potassium levels are what keep your heart beating regularly, and veering from normal ranges can disrupt this process. Mild hyperkalemia, which is usually identified by potassium levels from 5.1 mEq/L to 6.0 mEq/L, may not do too much to disturb your heart function, whereas moderate hyperkalemia, potassium levels

of 6.1 mEq/L to 7.0 mEq/L, can disrupt electrical activity of the heart, and severe hyperkalemia, which is 7.1 mEq/L and higher, can completely stop the heart from beating [2].

Another important consequence of hyperkalemia is its effect on skeletal muscle movement. When the sodium-potassium pathway is disrupted, this can affect the movement of muscles, causing them to spasm, weaken or paralyze [3]. Although not immediately life-threatening by itself, this can cause extreme discomfort.



What are the symptoms of hyperkalemia?

Symptoms of hyperkalemia can be unnoticeable, if they appear at all [1]. If symptoms do occur, they are often mild or easily dismissed, such as weakness or fatigue, muscle pains and cramps [4], numbness and tingling. These symptoms can come and go over the course of many weeks or months [1]. In sudden or severe cases of hyperkalemia, you may have shortness of breath, heart irregularities, chest pain, nausea or vomiting. Sudden or severe hyperkalemia is a very serious condition which requires immediate medical treatment [1].

What role does nutrition play in preventing hyperkalemia? What can you do to keep your potassium within a healthy and safe range?

If you have been told you have hyperkalemia at any point, talk to your doctor about what your best options are for lowering your potassium levels. Be sure to tell your doctor about all of the medications you are taking, including over-the-counter medications, vitamins, and supplements [5]. Your doctor may suggest taking further action to keep your potassium in normal range:

Follow a low potassium diet - There are certain foods that are higher in potassium that may be causing your hyperkalemia and need to be limited or avoided. Some of these foods are root vegetables such as potatoes and sweet potatoes, unless double-boiled, tomatoes, oranges, bananas, melons, and leafy greens, just to name a few. Either too much or too little potassium can be dangerous, so be sure to discuss with your healthcare provider how much potassium is right for you.

Avoid salt substitutes that contain potassium - some salt substitutes contain potassium as an ingredient. These should be avoided by most people who have kidney disease. It is perfectly safe to use non-potassium-containing seasonings.

Avoid herbal remedies and supplements - Unless your doctor has given you approval, it is best to avoid all herbal remedies and supplements, as these can have ingredients that can increase your potassium levels. Be sure to check with your healthcare provider if you decide you would like to start using any herbal remedy or supplement.

Use water pills or potassium-binding medications - If potassium levels cannot be controlled with lifestyle changes, your doctor may want you to start certain medications that can help lower potassium.

- Water pills, or diuretics, help you remove potassium from your body by helping your kidneys make more urine, which removes more fluid from your body,
- Potassium-binders are medications that "bind" potassium in your gut and take it out of your body. They usually come in the form of a powder and are mixed with a little water. They can be taken with food or once a day. It is important to follow the instructions when taking these medications, as they can interfere with other medications you are taking [5].

Untreated Hyperkalemia can lead to abnormal and life-threatening heart rhythms, but with some dietary and lifestyle changes, it can be an easily manageable condition. If you've been told you have high potassium, talk to your doctor right away about what you can do to better control your potassium levels. He or she will be able to help monitor your levels and make sure you are able to control this condition.

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Travel Lovers, Don't Let Dialysis Slow You Down

By Vanessa Evans,
DPC Board Member and Sr. Manager, Patient Communities and Advocacy at Fresenius Medical Care North America

Brenda and Bernie Alvey are the consummate camper travelers, crisscrossing the United States and taking in sights from the St. Louis Arch to the Grand Canyon. But their camper has a few unusual features, including two recliners, extra outlets, and a homemade stand to accommodate Brenda's portable home hemodialysis equipment.

The Alveys have always loved traveling, but they thought their trips had come to an end when Brenda was diagnosed with Membranoproliferative Glomerulonephritis (MPGN), an autoimmune disease that destroys kidney function.

Upon starting dialysis treatments in 2015, Brenda opted for home hemodialysis with the NxStage system, giving her the freedom to travel. Before the global pandemic, Brenda and Bernie traveled widely with a purpose, visiting dialysis centers to tell others about their success with home hemodialysis on the road.

Like the Alveys, I too love to travel

and travelled often before COVID-19 made it unsafe. I have discovered that with good planning and a can-do attitude, travel is possible when you are on home hemodialysis. I know this very well, as I have been on dialysis for over 23 years. I switched to home dialysis when my husband and I wanted to start a family and I have never looked back since. That was over 16 years ago, and today I have two boys, ages 14 and 16 years old. To my boys, dialysis is just part of our lives, including when we travel.

Admittedly, I was nervous about taking my first trip. But then I thought, "You can get over this, you can do it!" I took things slowly, starting with a trip to Cape Cod, where my family rents a house every summer. It was a familiar destination, and we could drive there rather than fly. I packed up my dialysis machine and all my supplies, and off we went. That first trip changed me. From then on, I knew that I could travel.

Since that first trip, I've made more than 40 – typically two or three a year – including flying overseas three times. I travel for work as well and have become a pro - I've picked up tips along the way that you, too, can use when it is safe to travel again.

Begin planning well in advance. Start by connecting with your care team at least 60 days in advance for domestic travel and eight weeks in advance for international travel so that they can help submit your travel prescription and make other arrangements, such as shipping supplies. I'd also recommend that you make a checklist of everything you'll need, including your machine, medical supplies, non-medical supplies, including, pliers, to undo stuck tubing, scissors, trash bags and an extension cord, as well as personal and medical information.

Travel can also be unpredictable, so there are things you can do to help prepare. Try and ship your supplies so that they arrive before you do. This way, you can check with the hotel or wherever you're staying to ask them how many boxes they've received to ensure it matches what was sent. I also ask them to text me a photo to make sure it's the right equipment. I also try to build in plenty of time to get to my destination, accounting for delays and issues that invariably arise during travel. I'll even dialyze the day before travel so that if there is a delay, I have a 24-hour buffer before needing a treatment.

If you're flying to your destination, there are some additional tips that I've found to be helpful during my travels. First, I advise that you bring a copy of the Department of Transportation Guidance on the Transport of Portable Dialysis Machines by Travelers with Disabilities with you to the airport. Among many other key pieces of information, the guidance states that, by law, airlines can't charge you for shipping your life-saving medical supplies within the United States, so pack your supplies in a separate suitcase from your clothes so you don't get charged. I also find it helpful to get a cart for your equipment and luggage and head to the check-in counter; or check your luggage and equipment with a skycap when you arrive at the airport.

For travel outside of the United States, ask your care team for insights and tips and research the rules for your destination, which vary. For example, you may have to pay additional fees to have your supplies delivered. It's an added expense and it's not easy, but it's well worth it.

Make sure to check with your insurance provider to get all the details on what is covered based on where you travel. There are many helpful resources available on the Fresenius Kidney Care and NxStage websites, including checklists, tips for travel and more.

When I arrive at my destination, the first thing I do is set up my machine to be sure everything is working, and I have all of the supplies I need. If I can, I dialyze first thing in the morning, which frees up the rest of the day.

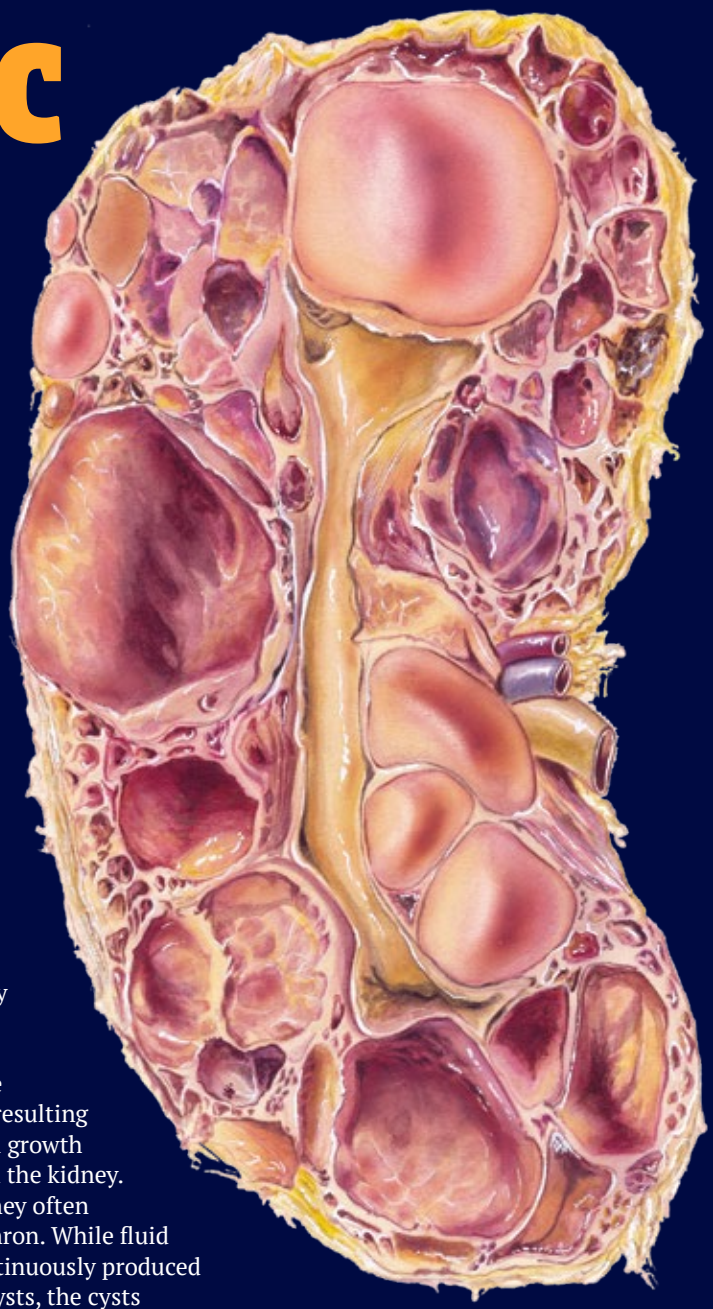
For your first trip, I suggest keeping it simple, such as a weekend at a friend's house or a hotel nearby. It will help you get comfortable with packing up your machine and supplies, and help you learn what works for you. While it is possible to travel if you are receiving in-center hemodialysis, home dialysis gives you flexibility and makes travel much more manageable.

If you love to travel, there's no reason to let hemodialysis slow you down. With good planning and the right attitude, exploring the world is well within your reach.

Bon Voyage and Happy travels!

Vanessa Evans has been on dialysis for over 22 years and lives in Boston, MA with her husband and two sons. A passionate advocate for the last 14 years, Vanessa does not let her diagnosis slow her down. She works full-time as the Sr. Manager of Advocacy and Communities for FMCNA. Vanessa has a master's degree from Emerson College and a BA in Political Science from University of Massachusetts, Amherst. She has presented for many organizations including: NKF, PCORI, ANNA, AAKP, FDA and HHS. She is considered an expert in patient experience and engagement.

Polycystic Kidney Disease (PKD)



By Mirjana Dimitrijevic, M.D.
and **Keith A. Bellovich,** DO

There are two major forms of PKD: autosomal recessive polycystic kidney disease (ARPKD) and autosomal dominant polycystic kidney disease (ADPKD).

ARPKD is uncommon and is typically diagnosed in infancy or in utero. Autosomal recessive means that the mutated gene must be present in both parents (carriers) with a 1 in 4 chance that a child will inherit an abnormal gene from both parents and have the disease. In ADPKD each child of an affected parent has a 50% chance of inheriting the disease.

ADPKD is the most common inherited kidney disease, characterized by the development of multiple kidney cysts and associated with other organs involved beside the kidney. This can be heart valve anomalies, cysts in other organs like the liver, pancreas or ovaries and diverticulosis in the colon. Prevalence rates are similar in all ethnic groups. It is caused by mutations identified in at least three genes and they are located on a different chromosome (PKD1 on chromosome 16, PKD2 on chromosome 4 and GANAB on chromosome 11). PKD1 mutations are more common, but PKD 2 disease is usually milder in severity and the need for dialysis.

Nearly 50 percent of patients will develop end stage kidney disease (ESKD) by age 60 in PKD1 versus 74 years in PKD2. ADPKD is 4th leading cause of ESKD requiring a kidney transplant or dialysis.

In PKD, tubules become structurally abnormal, resulting in the development and growth of multiple cysts within the kidney. When the cysts form, they often pinch off from the nephron. While fluid accumulates and is continuously produced within the expanding cysts, the cysts increase in size and number. Ultimately, they damage normal parenchyma which can result in ESKD. Cyst volume is strongly linked to functional decline in overall kidney function. Enlarged kidneys due to a high cyst burden expressed as total kidney volume (TKV) is the most important risk factor for progression to kidney failure. A kidney that is filled with cysts can weigh up to 30 pounds. A goal of current therapies is to target cyst growth before it disconnects from parent nephron.

Depending on the age of onset, signs of the presence of polycystic kidney disease can be found on a physical exam in the form of an enlarged abdomen, heart murmur and elevated blood pressure.

Ultrasound (US) is recommended as the first diagnostic test. However, it has a false negative rate of 16-18 percent before age 30. Computed tomography (CT) and magnetic resonance imaging (MRI) are more sensitive because they pick up smaller cysts. The limit of an US to detect a cyst is 1 mm and for CT and MRI it can be as small as 0.2 mm.

Genetic testing is usually reserved for unique situations. For instance, a young adult with a family history of ADPKD and a negative ultrasound who wishes to be a potential kidney donor, or a person whose ADPKD diagnosis is not certain based upon imaging tests or someone younger

than 30 years of age with a family history of ADPKD and a negative ultrasound who is planning to start a family.
Kidney enlargement always precedes a drop-in glomerular filtration rate (GFR). Loss of kidney function or drop in GFR is relatively late in the disease. Patient with ADPKD may remain asymptomatic for years while the disease progress. Once the GFR has started to decline it is often too late to reverse this process.

ADPKD patients suffer kidney complications prior to loss of kidney function. By age 30 over 50 percent have at least one complication.
Polycystic kidney disease complications can include kidney stones, hypertension, hematuria (blood in the urine), pain, infections, anemia, and cancer. Proteinuria (protein in the urine) is not common, but has important prognostic implications.
The best predictors to assess disease prognosis are total kidney volume (TKV), genetics, family history, early onset of hypertension, and hematuria.
TKV based classifications is helpful to identify patients at risk of rapid disease progression.

PKD can affect other organs besides the kidney. People with PKD may have cysts in the liver or pancreas, brain aneurysms, intestinal diverticulosis, hernias, and abnormalities of the heart valves.
A ruptured intracranial aneurysm (IA) or subarachnoid hemorrhage (SAH) is the most serious complication of PKD. Risk of rupture increases with size of aneurysm. Mortality is more then 50 percent when size is greater then 10mm.
Screening for asymptomatic patients is controversial based on available data.

Screening with MRA or CTA is recommended for patient with positive family history of IA or SAH, prior SAH, neurologic symptoms, hypertension, smoking, alcohol abuse, high-risk professions (such as pilots), or those undergoing major elective surgery.
There is no cure for ADPKD, but a new treatment is available that has been shown to slow the progression of ADPKD to kidney failure.

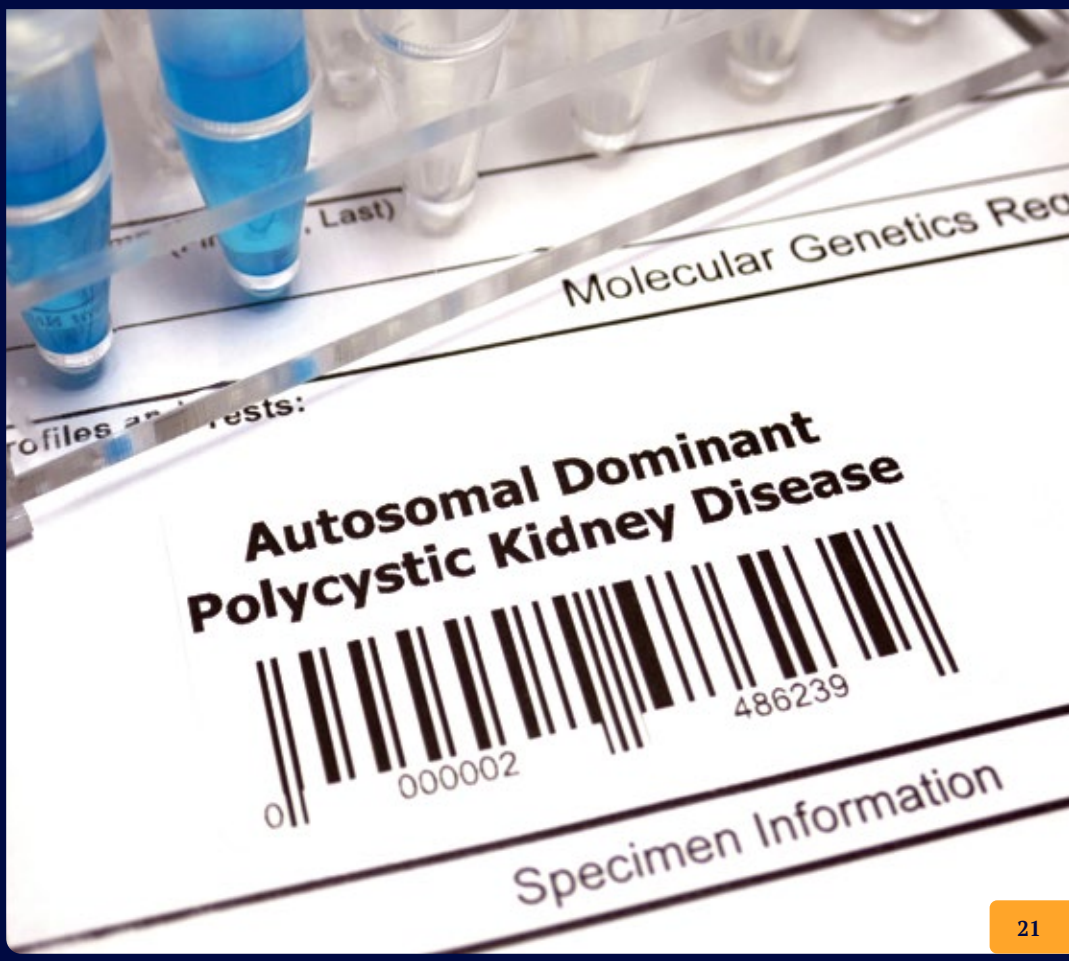
Treatment focuses on slowing the progression and treating the associated features of the disease, such as kidney infections or stones, flank, or abdominal pain. Nephrectomy (surgical removal of one or both of the kidneys) should be avoided. It is considered for a recurrent and/or severe infection, bleeding, stones, intractable pain and space restriction prior to transplantation.

There are conflicting findings on the benefit of a low-protein diet in people with ADPKD. Low sodium diet (2 grams per day or less) is recommended. Treating high blood pressure can have a dual benefit in people with PKD because it can help prevent heart disease and also reduce the likelihood of developing kidney failure. Based on previous studies blood pressure goal 120-130/70-80 mmHg reduces the rate of disease progression using angiotensin-converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs).

Data from 2 clinical studies that included over 3000 patients with ADPKD showed that tolvaptan slows kidney function decline in adults who are at risk for disease progression, based on kidney size for a given age and kidney function. In April 2018, the FDA has approved this medication. This is the only FDA-approved treatment that works to slow the decline of kidney function.
Tolvaptan is a type of drug called a vasopressin receptor antagonist. It can cause side effects including serious liver problems and should not be used in patients with liver impairment. It is important that you have a blood test before you start and while on treatment. Most often, patients experience frequent urination, urination at night, and increased thirst which tends to decline after several months on the medication.

People with ADPKD who require dialysis are usually treated with hemodialysis. Peritoneal dialysis is less commonly performed due to the presence of the enlarged kidneys but can be considered on an individual basis. The prognosis after kidney transplantation is usually excellent and does not recur in the transplanted kidney.
See the references below for more information and never hesitate to talk it over with your doctor.

www.pkdcure.org
www.kidneyfund.org
www.jynarque.com



Why DPC Fights To Maintain Private Insurance Coverage for Dialysis

By Jackson Williams,
DPC Vice President of Public Policy

In recent years, private insurance coverage for dialysis patients has come under attack. In 2016, the outgoing Obama Administration issued a regulation that would have prohibited charities like the American Kidney Fund (AKF) from assisting patients with premiums. Several insurers unilaterally refused to accept checks from AKF or eliminated dialysis providers from their networks. Some employers have tried to restrict coverage for dialysis by amending their health plan language. The SEIU labor union promoted legislation and ballot initiatives, most notably in California, to restrict or eliminate insurance coverage for dialysis.

DPC has been in the forefront of fighting off these attacks—in the courts, through lawsuits; bringing legal violations to the attention of regulators; and grass-roots efforts empowering patients to contact their legislators. As of today, DPC has been victorious, and patients have been able to keep their coverage.

These fights are often framed by the media as battles over the higher

reimbursements that dialysis providers receive from private insurers relative to Medicare. To be sure, those reimbursements help subsidize smaller and rural clinics that cannot break even on Medicare rates, and help maintain an extensive system of clinics closer to patients' homes. But even more is at stake for patients, as this article explains.

Coverage for Dialysis Incentivizes Better Care for CKD and Safer Transitions to ESRD

Medicare law gives patients the right to keep their commercial coverage for 30 months before switching. Why did Congress enact this 30 -month option?

The entitlement of people with ESRD to enroll in Medicare regardless of age creates a perverse dynamic in the care of persons with chronic kidney disease (CKD). Once an insured's CKD progresses to ESRD, the insurer may be able to offload that sick patient's expenses onto taxpayers. This means the insurer lacks the financial incentive to try to preserve the patient's kidney function as long as possible, or to prepare the patient for the CKD-ESRD transition by having a fistula created, educating the patient about home dialysis, or obtaining a pre-emptive transplant. To combat "short-timer syndrome" on the part of insurers, Congress in 1981 put insurers on the hook for some dialysis costs. Over the years their responsibility has been increased to 30 months.

We know what happens when a change in a coverage is triggered by deterioration in a patient's health, exemplified at its worst by the **nursing home bounce-back** phenomenon that plagues people dually eligible for Medicare and Medicaid. Nursing home care is generally paid for by Medicaid at a low rate, but after the patient is hospitalized he or she returns for post-acute care reimbursed by Medicare at a higher rate. The nursing home profits from the acute illness and the state is relieved from paying for long-term care during the post-acute period, making both parties indifferent to delivering high-quality preventive care. The 30-month requirement spares ESRD patients from this purgatory, and nobody has proposed any alternative mechanism.

The deterrent effect of the 30-month requirement is lost if the ESRD patient

(who typically may no longer work full time after kidney failure) can't afford health insurance. This is why the U.S. Department of Health and Human Services (HHS) approved the role of the American Kidney Fund in paying premiums.

There are Several Reasons Why Patients Might Prefer to Keep Private Coverage

The option to maintain private health coverage can appeal to individual ESRD patients for several reasons.

First, Dialysis Patient Citizens' 2015 Annual Membership Survey, conducted by the IPSOS international research firm, found that dialysis patients prefer private coverage. We asked several questions from the Consumer Assessment of Health Plan Survey (CAHPS) to gauge relative satisfaction with their coverage. We found:

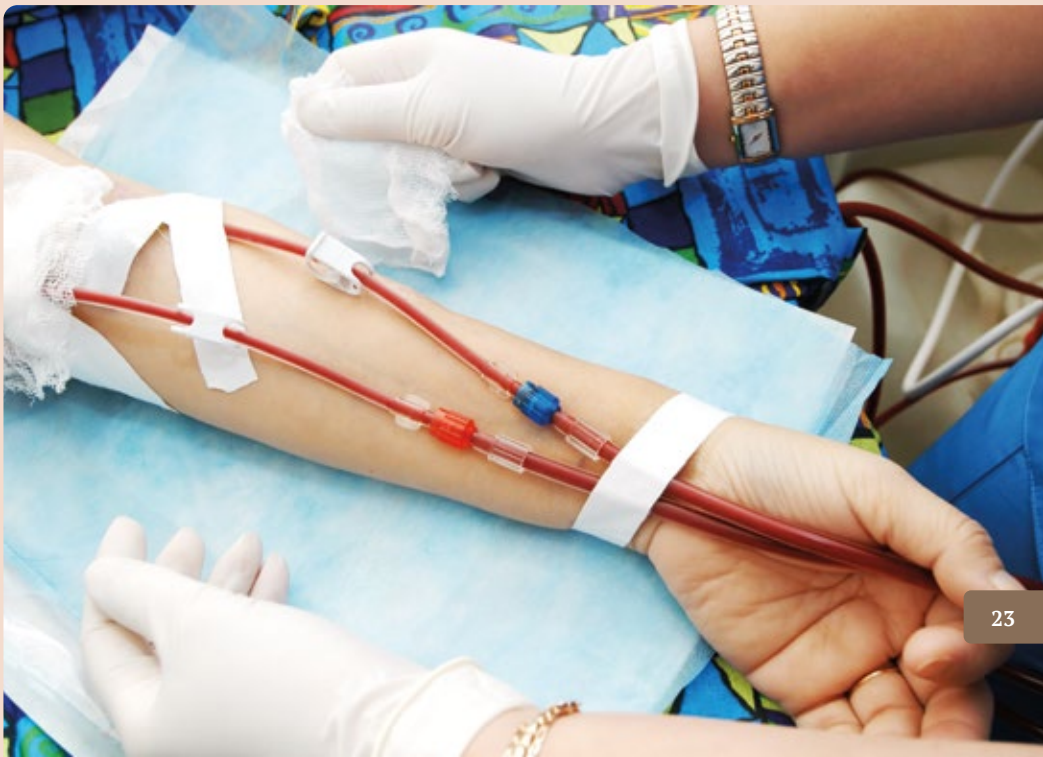
77 percent of patients rate their private health insurance as the "best health insurance plan possible," compared to 71 percent for Medicare.

Medicare beneficiaries are more than twice as likely as private health plan members (13% versus 5%) to report having trouble getting health care that they wanted or needed.

Medicare beneficiaries are more likely than private health plan members to report difficulties in getting the specific medication they need, difficulty getting someone on the phone to answer questions, and delays in receiving care or treatment.

Second, the federal Quality and Disparities Report finds 33 different measures on which better care is delivered through private insurance than public insurance. These include being able to get timely dental care; fewer deaths from heart attacks; better access to preventive services such as mammograms; and fewer deaths and other complications from hospital care.

Third, a recent study of CDC survey data found that people with multiple comorbidities who have employer-sponsored and individually purchased private insurance were less likely to have difficulty seeing a doctor, to skip medications, have instability in coverage, or report medical debt compared with individuals covered by publicly sponsored insurance programs.



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Kidney Disease and the Family

All parents desire for their children to be happy and healthy. So, finding out that your child has kidney disease can leave you and your child feeling sad, confused, and scared. This free course, developed in partnership with the American Psychological Association, will help you learn more about how your child's mental health may be impacted by this diagnosis and what parents can do to help them cope. It will also offer tips for siblings and parents.

Check out the course at:

https://www.dpcedcenter.org/resources/online-courses/kidney-disease-and-the-family/