

THE DIALYSIS
P.A.T.I.E.N.T. ACT



4

COMMON WITH
PERITONEAL DIALYSIS



8

THE GOUT AND KIDNEY
CONNECTION



12



THE KIDNEY CITIZEN

A publication of Dialysis Patient Citizens (DPC) Education Center



President's Message

I want to take this opportunity to thank you for your continued support. While Dialysis Patient Citizens (DPC) Education Center is a relatively new organization, we are fortunate for all of the assistance we continue to receive from you to help us further empower kidney disease patients. We greatly appreciate all of the feedback and input that you continue to provide for the Kidney Citizen, as well as to our many other educational resources. I am also humbled by your generous contributions to advance our educational efforts. In this issue, we highlight one such contribution by the Fraternal Order of the Eagles in memory of Eckman Short, a dedicated caregiver for his daughter who was diagnosed with a rare form of kidney disease.



As you know, our mission is to improve kidney patients' quality of life and reduce the occurrence of ESRD through education. Education is not limited to only the clinical aspects of your care, it's important to be aware of policy changes that can affect your care quality as well. That is why I want to make sure that you are aware of new legislation in Congress called the Dialysis PATIENT Demonstration Act (H.R. 5506/S. 3090). This bipartisan bill was recently introduced in both the House of Representatives and the Senate. It would allow dialysis providers and others to coordinate care for patients while increasing patient engagement in their care. The goal is to test additional models of care to improve patient outcomes. Detailed information, including examples of current care coordination efforts, was provided in our last issue of the Kidney Citizen. In this issue, you can read more about the Dialysis PATIENT Act itself.

Most importantly, I wanted to draw your attention to three pre-printed, customized postcards to your Senators and Representative in support of the Dialysis PATIENT Act included in this issue of the Kidney Citizen. Since many in Congress are focused on the upcoming November elections, we need your help to ensure that they are also paying attention to how they can help dialysis patients. We urge you to sign these postcards and mail them back to us today. Remember, these are postage-paid postcards, so you simply need to drop them off in a mailbox. Once you drop the postcards in the mail, they will go directly to our office in Washington, D.C., where our staff will deliver your messages of support to your legislators, bundled with others from your State and Congressional district. As a patient-led organization working to further empower patients, we are counting on your support. Thank you again for everything you do to help ensure our success. ■

Sincerely

Nancy L. Scott
Nancy L. Scott

DPC Education Center
Board President

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Fraternal Order of the Eagles Honors Eckman Short's Memory

By **Heather Strobel**, Director of Development, DPC Education Center

In February of this year, the Fraternal Order of the Eagles 871 of Alexandria, Virginia honored the memory of Eckman "Pete" Short with a generous donation to the DPC Education Center. Pete was a long time member of the Fraternal Order of the Eagles, an international non-profit organization promoting peace, hope, and community that donates millions to charities annually. His life was a living example of our mission to improve kidney patients' quality of life, as he was a dedicated caregiver and advocate for his daughter's health and her battle with a rare kidney disease.

Eckman "Pete" Short was a beloved husband, father, brother, grandfather, and friend. Pete was a long time resident of Alexandria, Virginia and spent his childhood in War/ Yukon, West Virginia, as the son of a coal miner. In the 1960's, following in his brother's footsteps, Pete relocated to Alexandria, Virginia, where he worked with a number of roofing companies in the area before starting his own business.

Pete eventually married and had three daughters. His middle daughter, Tracy, had a rare kidney disease that came to light three and a half years ago. Pete served as a caregiver to his daughter Tracy, as she underwent dialysis until a transplant became available. Pete was dedicated



to ensuring that Tracy received dialysis three times a week and would often rearrange his business schedule to make certain that she was driven and picked up from the DaVita Dialysis Center, where she received her treatment.

The staff at DaVita was amazing in the compassion they had for Tracy. Tracy also was developmentally challenged, and knowing this, they took extra steps to make sure she was comfortable and understood the procedures.

Pete passed away on September 4, 2015 from Hemophagocytic Lymphohistiocytosis (HLH), a life threatening immunodeficiency disease. His daughter Tracy passed away shortly after from renal failure on September 22, 2015. Pete's dedication to his daughter and advocacy for the highest possible care of her kidney disease was

an important part of his life, and his memory is honored by those who knew him.

The generous donation to the DPC Education Center by the Fraternal Order of the Eagles 871 in memory and honor of Eckman Short helps us continue our mission. Without the continued assistance from donors like the Fraternal Order of the Eagles and others in the kidney community, we would not be able to carry out our vital mission in providing education, and support to patients to help improve their quality of life. ■

The Dialysis P.A.T.I.E.N.T. Act: Additional Support for Patients with End Stage Renal Disease

By **Jackson Williams**, Director of Government Affairs, Dialysis Patient Citizens

Bipartisan legislation has been introduced in Congress that will expand ESRD patients' access to the latest innovative care techniques. The Dialysis PATIENT Act (Patient Access to Integrated-care, Empowerment, Nephrologists, and Treatment, H.R. 5506/S.3090) will establish a new ESRD Integrated Care Demonstration Program within Medicare to build on successes achieved in previous demonstrations and in the Special Needs Plans that serve beneficiaries with ESRD.

Through previous pilot projects, techniques have been developed that improve some of the most important quality indicators including: fewer patients using catheters; more patients using home modalities; and reduced hospitalizations. Kidney failure usually results from co-morbidities such as hypertension and diabetes that continue to afflict the patient. In Original Medicare, those conditions are treated separately from renal care; in coordinated care programs, these conditions can be addressed by the ESRD care team, using the dialysis clinic as a "hub."

If you think of your dialysis care as a salad, care coordination does not change that salad. But, if you need an additional treatment or more time on your machine, your dialysis facility will give it to you - turning your salad into a double. If you have diabetes, your dialysis facility can

now hire a health coach to help you - think of it as seafood added to your salad. What about all the medications that you are on? They can hire a pharmacist to make sure you avoid risky complications and help you with sticking to your drug regimen - the avocados on the salad.

So, while you get a high quality salad from your dialysis facility, you may want (or need) all the fixings. There is nothing wrong with a good quality salad, but we want to make sure you can have it your way, even if it means it is loaded with everything. The main difference is that these "fixins" may help to keep you out of the hospital, prevent an amputation, and help improve your quality of life as you are further empowered with additional support for your care.

Today, only a relative handful of patients are served by integrated care programs. The purpose of the Dialysis PATIENT Act is to permit more dialysis clinics to offer these services. The congressional sponsors proposed an arrangement that is very favorable for patients: while your dialysis clinic can form a provider network to serve you, you would not be bound to stay within that network unless you actively chose to enroll in a limited network in exchange for additional benefits. You can obtain all of the care coordination services while keeping your freedom of choice to see any Medicare provider. ■

You can let your representatives in Congress know that you support expanding integrated care by signing and returning these postcards to DPC. DPC will take your messages directly to your Representative and Senators on Capitol Hill.

The table below summarizes what most patients receive from Medicare now and what they could expect under the Dialysis PATIENT Act:

Original Medicare	Dialysis PATIENT Act
Your dialysis clinic is paid only to provide dialysis care and other ESRD-related services.	Your dialysis clinic becomes the “quarterback” of all your health care needs and is responsible for coordinating with your other Medicare providers.
Freedom of choice to see any Medicare provider.	Freedom of choice to see any Medicare provider.
If you have to go to the hospital, the discharge instructions may be extensive and difficult to comply with in a timely manner.	The dialysis clinic has personnel assigned to work with hospitals to obtain discharge information, assist in scheduling follow up appointments, and confirm whether any medication adjustments are needed.
You, the patient, are responsible for coordinating between your renal care, hospital care, and primary/specialist care for other conditions.	The integrated care organization employs a nephrologist-led interdisciplinary care team, including a dedicated integrated care nurse to coordinate your renal care, hospital care, and primary/specialist care for other conditions, including assistance with referrals and making appointments.
If you go to the hospital because of an avoidable complication, your dialysis clinic is penalized in the amount of your missed dialysis sessions, or about \$250 per treatment.	If you go to the hospital because of an avoidable complication, the dialysis organization must pay for the cost of your hospitalization, or roughly \$15,000.
If you experience emergent fluid overload, you will likely have to go to the hospital.	If you require additional time on dialysis to remove excess fluid, the dialysis clinic has the flexibility, and the incentive, to provide it at no extra cost to you or Medicare.
You, the patient, may have a combination of health care and other needs that each provider, individually, cannot solve.	The integrated care team works to collect information from all providers, holistically evaluate your needs, and function as your health care advocate so that you get the right care at the right time.

2016 Advocacy Day Recap

By **Kristy Lukaszewski**, Policy and Communications Director,
Dialysis Patient Citizens



After weeks of planning, Dialysis Patient Citizens welcomed 30 patients and family members to Washington, D.C. to meet with their legislators on a beautiful spring day in April. As you may know, last year our advocates were snowed in. So, we were very grateful for the warmer temperatures this time around! The patient ambassadors who attended this year's advocacy

day traveled from 20 different states and had experience with all modalities; transplant, in-center hemodialysis, home hemodialysis and peritoneal dialysis. We were joined by 15 partners in care, nurses, social workers and facility administrators, to join our advocates on the Hill. This partnership allowed us to have 106 meetings throughout the day covering 32 different states!



The event began with an afternoon of training the day before to discuss the basics of holding a successful meeting, as well as, to learn more about the issues we would be discussing during our meetings. We were fortunate to have two guests, Dr. David Roer and Bridget McCoy, who traveled from Philadelphia to present to our advocates on the importance of integrated care, in addition to providing insight on how integrated care measures could improve their overall health and well-being. Their presentation provided the perfect framework to talk about the issues for this year's advocacy day; opening enrollment in Medicare Advantage to dialysis patients and supporting future integrated care legislation.

Both issues center around dialysis patients having access to increased coordination of care tools which can keep many patients out of the hospital while improving their health outside of their kidney disease. After hearing about the issues from DPC staff and our special guests, patients got into their state groups and started planning their meeting strategy for the next day. Patients were grouped up with at least one health professional from a neighboring state to maximize their impact and minimize any anxiety about

visiting with legislators, many were doing this for the first time! Once the strategies were set, it was time for dialysis where our advocates received treatment in one of three local dialysis clinics.

Breakfast was bright and early the next morning and then it was off to Capitol Hill. After a quick group picture, advocates went their separate ways to conquer a day full of meetings. We were able to deliver our messages to lawmakers to let them know how we think they can help improve the lives of patients with kidney disease. Believe it or not, nothing is more impactful to them than hearing from those that are directly impacted. Year after year, I am amazed at the patient stories the congressional staff hear during these meetings. Our advocates truly are dedicated to elevating the voice of ESRD patients across the country. This year was no different. After 106 meetings, patient advocates returned to the hotel excited and motivated to cultivate relationships with congressional staff and engage more patients in their home facilities.

If you are interested in becoming a Patient Ambassador, visit <http://dialysispatients.org/get-involved/patient-ambassadors>. ■

What Fluid Removal and Blood Sugar Have in Common with Peritoneal Dialysis (PD)



Do you like strawberry shortcake? Have you ever made it or watched your mother or grandmother make it? A few quarts of fresh strawberries, hulled and sliced in an extra-large bowl; a cup or two of sugar sprinkled over the top and stirred in with a big spoon; then into the refrigerator it goes for a couple of hours. When it comes out, oh let the copiously sweet strawberry juices flow! How does that happen? It's the sugar that chemically draws the fluid out of the strawberries. The dextrose, or sugar in the PD solution, acts the same way as the sugar on the strawberries do to draw extra fluid out of your bloodstream and into the drain bag. However, when you are a patient with diabetes, there is sometimes a higher concentration of sugar than

By **Barbara L. McKie** MSN, RN, CNN
Peritoneal Dialysis Coordinator
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normal in your bloodstream. This can be controlled by adding insulin to your PD solution. Is your blood sugar controlled, or does it run 200 mg/dL or higher? If a blood sugar is uncontrolled at 200 mg/dL or above, then the fluid will not come out of the bloodstream because the sugar in the bloodstream is almost or equal to the sugar in the fresh solution dwelling in your peritoneal cavity.

I once had a patient who came into my office extremely angry. He wanted off PD because “it doesn’t work!” His legs were extremely swollen; he had shortness of breath and just feeling miserable. He said that he had been using 4.25% for several days and no extra fluid was being removed at all.

The patient didn’t realize that his consistently very high blood sugars prevented any fluid movement. In other words, the sugar in his bloodstream was close to or equal to the concentration of sugar he had dwelling. So, in order for PD to work, the sugar level in your blood must be lower than the concentration of sugar in the solution. A

very important point here is that if your sugar is high, it makes you thirsty. When you’re thirsty, you drink. The more you drink, the more fluid your body will hold on to making your tissues very puffy. So naturally one would choose the highest concentration, or 4.25%, to take off the swelling. When this patient checked his blood sugar in my office, it was 380 mg/dL. So, he was caught in this vicious cycle. Once he got control of his blood sugars, he was able to keep from getting fluid overloaded. To get help with his blood sugars, he contacted his Endocrinologist who helped him improve his blood sugar control. So, what do fluid removal and blood sugar have in common? Sugar. To get the fluid off, use a high concentration sugar in the PD solution; to keep the fluid off, maintain a blood sugar level well below 200 mg/dL at the most. That way you won’t get thirsty, and drink and get caught in the vicious cycle. If you have trouble controlling your blood sugar, please see your Endocrinologist or ask your Primary Care Physician for a referral. ■

Ask a Nephrologist (and Psychologist!)

answers provided by **Dr. Jim Boudreau** and **Dr. Teri Boudreau**

1 I am thirsty most of the time and have difficulty following my daily fluid restriction. What can I do?

Nephrologist's answer: You can keep track of the volume of fluid that you are drinking by using a measuring cup to measure all fluids that you are ingesting. Sucking on frozen grapes or chewing gum also may help.

Psychologist's Ideas: Tracking fluids can be made easier by finding a system that is easy to access (e.g., calendar near where you eat, notes page on your phone, decorative journal that you enjoy using). Finding activities that you find pleasurable which are scheduled throughout the day can provide positive distractions until you are able to eat or drink a food or beverage.

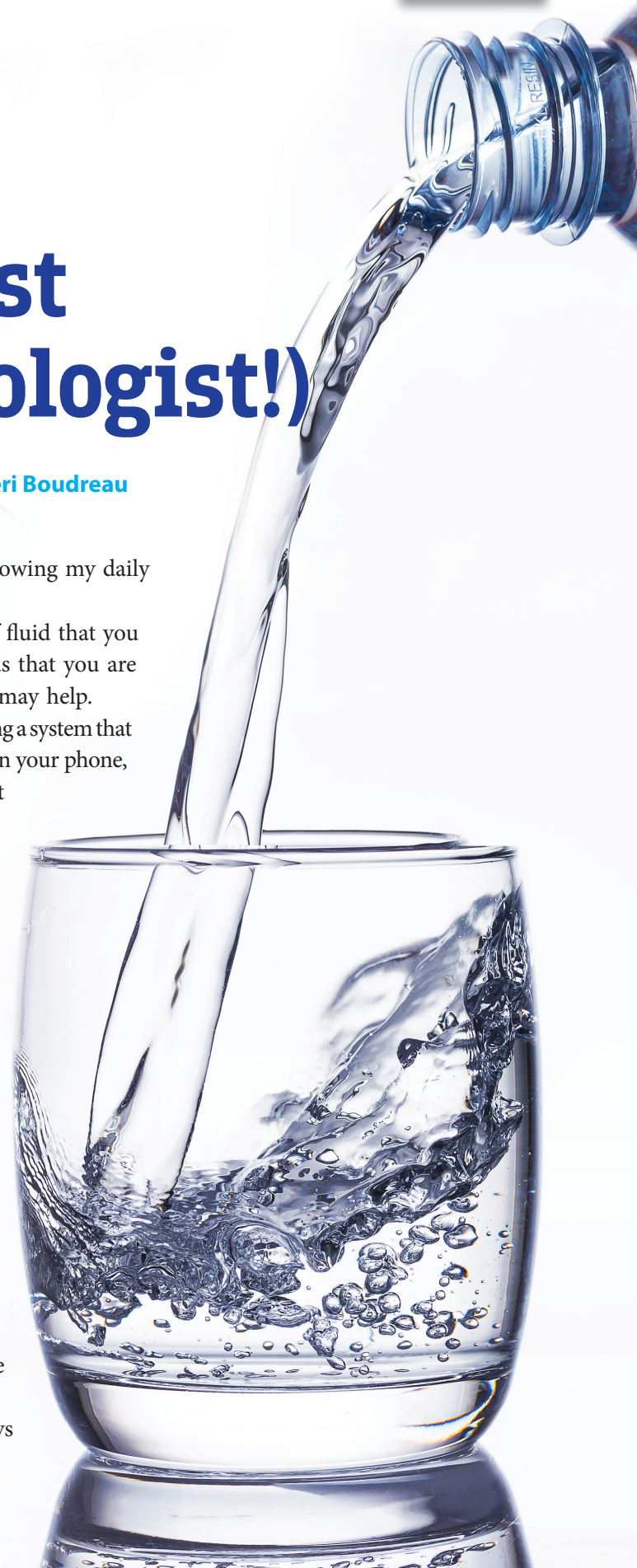
2 It is uncomfortable to sit in the dialysis recliner chair for four hours. Why can't my treatments be shortened?

Nephrologist's answer: Shortening your dialysis treatments will decrease their effectiveness: there will be incomplete removal of the waste products of metabolism. Fluid that needs to be removed will be left behind (and therefore will build up in your body). Long term, the duration of your life may be shortened.

Psychologist's Ideas: Getting to know the other dialysis patients can provide extra social support and shared enjoyment during an otherwise less than "fun" experience. Some dialysis patients find this is a good time to meditate, relax, and engage in certain hobbies. Reframing the negative thoughts into ones that focus on positive aspects of the experience can help improve both mood and attitude.

Negative thought: "Sitting in this dialysis chair so many days for such a long time is unpleasant."

Positive reframe: "Dialysis means improved health,



more active involvement in my life, positive interactions with other patients who may feel similarly to me, and an opportunity to use this time to reflect on all the positives in my life.”

3 Why do I have to take intestinal phosphorus binders? I like foods that contain phosphorus and do not feel any differently after I eat them.

Nephrologist’s answer: Through a series of steps, high blood phosphorus levels will cause calcification of your blood vessels and soft tissues, weaken your bones, and cause itching of your skin. Clinical studies have shown that elevated blood phosphorus levels, either by themselves or in association with high blood calcium levels, can increase mortality in dialysis patients.

Psychologist’s answer: Again, reframing the thought about why do I have to take intestinal binders into a positive thought about how fortunate we are that science allows us to take a medication that can allow us to eat some of the foods we enjoy while minimizing the negative consequences. Taking these binders allows us to more actively control our health rather than feel it is completely beyond our control.

4 Why are you recommending that I have an arteriovenous fistula (AVF) created? I do not like needles and would rather be connected to the dialysis machine using a catheter.

Nephrologist’s answer: Although it is convenient to receive your hemodialysis treatments via a catheter, your risk of experiencing a bloodstream infection (which can be fatal) is much higher and the quality of your treatments is lower. Furthermore, taking a shower and swimming are not allowed with a catheter. Numbing cream or cold spray may be prescribed to lessen the feel of the needles.

Psychologist’s answer: There are many techniques for feeling more relaxed when thinking about needles. Preparing by relaxing prior to procedures can be quite useful for some, but relaxation can also increase the vasovagal response leading to lower blood pressure and fainting. When a person is having this experience, applied tension can be useful. Applied tension involves tensing and releasing muscles groups to increase blood pressure and counter the body’s response of decreased blood pressure. It can obviously be more painful to be tensing a muscle during an injection, so it is recommended that



a patient tense the opposite arm or leg or another part of the body. You can take a small tension ball to squeeze in the alternate hand. You can ask your healthcare provider if you want more information on this technique.

Positive reframe: “Taking a shower and swimming mean less restriction and increased freedom.” “I can control my discomfort or worry about needles so that I get the best healthcare.”

5 Why do I feel exhausted after completing my hemodialysis treatment?

Nephrologist’s answer: Typically, standard hemodialysis attempts to accomplish in 12 hours what normal kidneys do in 168 hours, when viewed from a weekly frame of reference. Thus, the rate of removing fluid and the waste products of metabolism occurs much more rapidly than is the case without kidney failure. In addition, the body electrolytes and minerals are ‘normalized’ rapidly as well. These changes result in one’s feeling ‘washed out’ and tend to be more profound the older one’s age.

Psychologist’s answer: Increasing overall health can help to counter some of this effect. Focusing on eating well, having good sleep hygiene, and exercising (getting some activity) daily increases overall health and feelings of well-being. It can be helpful to plan activities mindfully around your dialysis schedule so that you maximize energy levels. Tuning into when you can push and acknowledging that you feel tired because your body is “regrouping” and “recharging” after dialysis can be helpful. For some patients, fatigue is a motivator to ingest less fluid between treatments so that the body experiences less stress during dialysis. ■

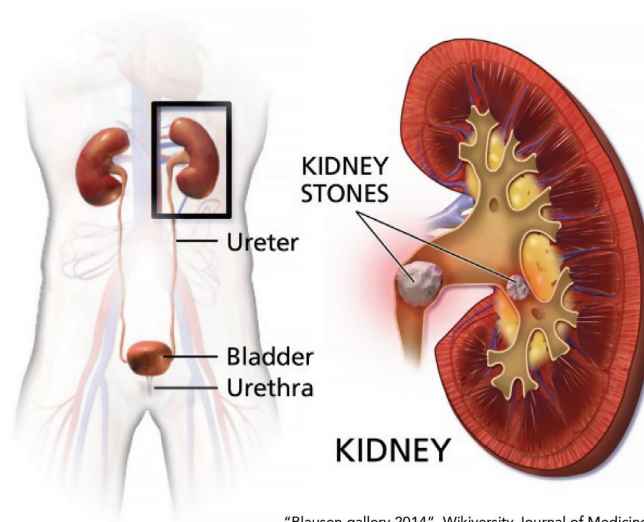
The Gout and Kidney Connection

By **N. Lawrence Edwards**, MD, MACP, MACR
Rheumatologist and Chairman, Gout & Uric Acid Education Society

Gout affects a growing number of people worldwide – and an estimated 8.3 million Americans – yet, the disease remains widely misunderstood. While gout incidence is on the rise in the U.S., research from the Gout & Uric Acid Education Society has shown that many people do not recognize gout as a “serious” condition. However, if left untreated, gout can have devastating health consequences – especially for those with existing kidney problems, such as kidney disease or kidney stones.

Gout is caused by an accumulation of uric acid crystals in the joints and other tissues. Over time, these crystals can lead to painful attacks of gout, which are characterized by sudden pain, warmth and swelling in one or more joints. While people who have gout know very well that it is painful – with the majority ranking their pain as a nine or 10 on a standard pain scale – they do not always understand that gout is a chronic issue that requires immediate and lifelong treatment, beyond treatment during a flare-up. If uric acid levels are not lowered in a person who has gout, flares will persist over time and permanent damage to the joints, bones and tissue can occur.

While those who have gout are more likely to have kidney disease – an estimated 83 percent more likely, according to recent research – those who have kidney



“Blausen gallery 2014”. Wikiversity Journal of Medicine

disease are also more likely to suffer from gout and elevated uric acid levels. Uric acid typically dissolves into the bloodstream, processes through the kidneys, and leaves the body through the urine. However, in patients with kidney disease, it will be more difficult for the kidneys to get rid of uric acid, which not only increases the risk for gout, but also may contribute to decreased kidney function and worse outcomes.

It is important for treatment to begin early – even at the initial attack – to avoid long-term damage. Once a gout diagnosis is made, steps need to be taken, including lowering uric acid to the recommended level of below 6

mg/dL. For the large majority of people, a typical treatment plan includes taking uric acid-lowering medications to keep uric acid at a healthy level. However, because many gout medications can be potentially harmful to the kidneys, many physicians who treat patients with kidney problems put more emphasis on treatments beyond medications, such as lifestyle changes. Specific treatment recommendations for people with kidney problems may include getting regular exercise and maintaining a healthy weight; staying hydrated; and carefully managing diet by avoiding certain foods that are high in purines (i.e. red meat, seafood and beer) and foods that contain high-fructose corn syrup.

The gout and kidney connection is clear – when the kidneys have been compromised, they may not be able to process uric acid, causing it to buildup in the bloodstream, which can ultimately lead to gout. However, people with kidney disease or other related kidney problems can reduce their risk for gout through a proper treatment plan. Early diagnosis and ongoing treatment and management are critical to preventing future gout flares and long-term kidney damage.

The Gout & Uric Acid Education Society is a nonprofit organization made up of health care professionals whose mission it is to educate the public and health care community about gout. To learn more, visit GoutEducation.org. ■

TIPS FOR CONTROLLING GOUT AND PROTECTING YOUR KIDNEYS

If you have gout, hyperuricemia or kidney disease, talk to your doctor to learn how you can protect your health and prevent long-term damage.

- **Know your numbers.** Routine blood tests can check to see if you have elevated uric acid and to measure your kidney function (glomerular filtration rate).
- **Take medications as directed.** Your doctor may prescribe medications to keep uric acid levels low and gout flares at bay. Medications must be taken as prescribed, and should not be stopped – even if levels improve – without consulting a doctor.
- **Drink plenty of water.** Drink at least eight cups of water a day to help flush the kidneys and remove uric acid from the bloodstream.
- **Avoid trigger foods.** Your doctor may ask that you stay away from high-purine foods (red meat, shellfish and alcohol) and those that contain high-fructose corn syrup (processed foods and soft drinks).
- **Make healthy lifestyle choices.** Exercise regularly and maintain a healthy body weight. Avoid smoking.
- **Control other health issues.** Obesity, high blood pressure, high lipid levels and diabetes can elevate uric acid – leading to gout flares and damaging the kidneys.
- **Tell your doctor what medications and supplements you are taking.** Some may be raising your uric acid level.

Tornadoes, Hurricanes and Blizzards, Are you ready?

By **Mike Guffey**, Dialysis Patient Citizens Board Member,
KCER Infectious Disease Workgroup Co-Chair

“Be prepared.”

This may be a familiar phrase from your childhood, as it is from mine. However, it is also a good motto for dialysis patients and their families, especially as we head into the summer months with threats of severe weather throughout the country.

In addition to serving on the Board of both Dialysis Patient Citizens and the DPC Education Center, my “day job” is as a full-time Business Continuity Planner for a Midwestern financial institution with offices throughout the country. A large part of my job is to keep my company prepared for various potential service disruptions, many of the most common of which include weather-related events, ranging from tornadoes and hurricanes to blizzards and flooding.

Kidney patients are a special community that particularly needs to plan ahead for potential disruptions, no matter where along the kidney disease spectrum they may fall. It is critical for dialysis patients to make their necessary treatments, but it is also critical for transplant patients to continue taking their medications during such an event, and for pre-dialysis patients to follow their prescribed diets as well to help prevent the need for dialysis if possible.

In that spirit, here are some suggestions we all can follow to help prepare ourselves and our families for any local weather-related incidents or other disruptions.

- Plan ahead. A lot of the tools listed below are easy to find normally, so gather as much as possible now rather than waiting for a situation to occur.
- Maintain a Patient Identification card or other document with all of your personal contact information and medical needs: health status, nephrologist’s name and number, pharmacy name and number, insurance information, medication list, allergies, hepatitis status and other special needs.
- Keep two copies of your medical information and other important documents: one at home and one at another site not in the same neighborhood.
- Know how to contact your dialysis provider and their emergency patient hotline in case your local center is impacted. Re-establish contact with your center as soon as you can after a disruption.
- If possible, map out multiple routes to/from your center in case your primary route is not available. If you have transportation to your center, be aware of their emergency capabilities or alternatives. Make alternative arrangements for transportation if your provider is

not available (e.g. family members, neighbors, church members).

- Make sure your entire family is aware of your plans and trained to react. Children need to know addresses and phone numbers as well because “the white house by the park” may not be enough to get them to that location.
- When planning with children, it is often less threatening to plan around an absurd event. That is one reason many schools have enacted plans around zombie attacks or similar make believe situations.
- Prepare within your budget constraints. Do what you can afford. Don’t strain your finances laying in supplies. Try to do it over time, focusing on items that do not expire quickly.
- Understand the Emergency Kidney Diet and make sure you have supplies available to follow it in case you need to miss one or more treatment(s), which hopefully will not occur.
- If you are on home dialysis, maintain sufficient dialysis supplies to cover at least a week of treatments.
- Pay attention to the emergency training provided by your center so you know how to disconnect yourself and take shelter at the clinic if so directed.
- Always try to carry your identification with you and have some cash on hand during a disruptive event. A lot of stores will not have working credit card machines after a disaster, so cash does become king.

This information and more can be found online from various resources including the large dialysis providers,

governmental sites (Ready.gov, FEMA.gov, CDC.gov) and preparedness/recovery organizations (RedCross.org, EmergencyPreparednessEssentials.org). For those without computers, information is also available from local health departments and many state and local emergency preparedness sites.

Additionally, kidney patients have a resource dedicated to providing information on emergency preparedness with the Kidney Community Emergency Response Coalition (KCER). KCER’s mission is to “(c)ollaboratively develop, disseminate, implement, and maintain a coordinated preparedness and response framework for the kidney community.” Their website (kcercoalition.com) includes original documents specific to kidney patients, including the comprehensive KCER Resource Toolbox, as well as links to external sites like those listed above.

My involvement with DPC and the DPC Education Center led to my own involvement with KCER about three years ago. I was invited to join the KCER Pandemic and Infectious Disease Workgroup (speaking of ways to really put a damper on social introductions and ensure an empty seat on planes). My particular workgroup focuses with ensuring the kidney community is up-to-date on topics like the pandemic flu, Ebola, and the newest four-letter word, Zika. We work with the dialysis providers, the ESRD networks and external agencies such as the CDC to create educational materials for dialysis patients to prevent these serious diseases from being contracted. In the past month, I have volunteered to be the workgroup co-chair. ■

The Rise of Donors with Increased Risks of Infection Transmission: What it Means for you as a Patient Awaiting Transplantation

By **Dr. John Swanson**, Director Kidney Transplant Program
at Christiana Care Health Systems

There is a major shortage of kidneys for the many patients that are waiting for a transplant. So, the transplant community has looked for ways to safely increase the number of kidneys available to the thousands of patients awaiting transplantation. One of the ways to increase the number of kidneys available is to consider donors that the Public Health Service (PHS) has determined to be at increased infectious transmission for Human Immunodeficiency Virus (HIV), hepatitis C virus, (HCV) and hepatitis B virus (HBV).

This group of donors now makes up about 30% of all donors available. These donors have tested negative for HIV, HCV, and HBV but have medical or social histories that suggest they could have been exposed to HIV, HCV and HBV which could then be transmitted to an organ recipient with transplantation.

People that are at higher risk for HIV exposure are also at higher risk for exposure to HBV and HCV. To protect our patients from harm, the Public Health Service has developed a list of factors that includes persons who

use intravenous drugs, engage in sexual practices that put them at increased risk of sexually transmitted diseases, were in prison within one year of their death. Donors who do not have one of these factors but who receive a large amount of blood products prior to their death are also considered at increased infectious risk.

Many transplant centers have studied the question of using such organs from deceased donors who have been determined by PHS criteria to be at increased risk for exposure to HIV, HCV and HBV. These donors often have organs that are of otherwise excellent quality. The results of studying these transplant recipients have shown excellent outcomes with no disease transmission at present. This does not mean that there is no risk.

It is assumed that the risk of transmission of HIV from a PHS risk donor with negative testing is about 1:1500 (one person for every 1500 persons transplanted), or the same risk as dying in a house fire; to 1: 10,000, the risk of drowning in your bathtub.

Testing for HIV, HCV and HBV has improved for

deceased organ donors and the test results are extremely accurate and sensitive. However, there is a short window period of about 5-6 days, from the time of exposure to HIV to when the virus can be detected in the blood. This period is shorter for HCV (3-5 days) and slightly longer

Please ask your transplant care provider any questions that you or your family may have.

■



for HBV (20-22 days). This means that, if a potential donor had been exposed to one of these viruses in recent days, the blood tests would not show it, and the virus could be passed to the recipient. All deceased donors are tested for HBV, HCV and HIV.

Willingness to accept an organ from a PHS donor can shorten the time that a patient has to wait to receive a transplant. The risks of dying on dialysis while waiting for a kidney may be greater than the risks of getting a transmissible infection from such a donor if transplanted. However, these PHS risk organs may not be a good option for all transplant candidates, and there are many factors to be considered. Your transplant center will be able to provide you with as much information as possible about such potential donors, so that you can make the most informed decisions possible.

Here are some important facts to understand:

1. **You do not have to agree to accept a high-risk donor if you do not want to.**
2. **If you say that you do not want to consider PHS acceptable risk donors, your status on the transplant waiting list will not change, but patients that do agree to consider these donors can sometimes be transplanted more quickly.**
3. **Willingness to accept a PHS acceptable risk organ does not affect your chance of receiving a transplant from a standard risk donor.**
4. **You can change your mind at any time and it will not affect your status on the transplant waiting list.**
5. **You should discuss any questions you have about these types of organs with your transplant coordinator(s) and/or transplant physicians.**
6. **If you do receive a transplant from a PHS acceptable risk donor, you will be tested more frequently for HIV, HBV and HCV for up to a year after transplant.**

Should you have further questions regarding this issue, please feel free to contact your transplant team.



Phosphorus and Dialysis

By **Shadi Fattah**, RD, LDN

Phosphorus is an essential mineral found mostly in bones and teeth and is the second most abundant mineral in the human body after calcium. It has many functions in the body including growth and repair of body cells and tissues, energy use and storage and use and balance of different vitamins and minerals.

Healthy kidneys are able to get rid of extra phosphorus that doesn't get absorbed or stored. When you are in kidney failure, the kidneys aren't able to remove the extra phosphorus. This leads to a buildup of phosphorus in the body and can become very dangerous.

Too much phosphorus can lead to;

- Weak and brittle bones; can lead to bone fractures

- Non-healing sores; can lead to amputations
- Stroke
- Heart attack
- Death

There are three ways you can keep your phosphorus level in goal range

- Completing your dialysis treatments
- Take your phosphate binders (if prescribed by your doctor)
- Limiting high phosphorus foods

Dialysis helps remove some of the extra phosphorus that isn't used in the body. If you are on hemodialysis, whether in-center or at home, complete all your treatments. If



you're on peritoneal dialysis, make sure you do all your exchanges as prescribed by your PD nurse and doctor. Missing treatments/exchanges or cutting treatments short can lead to a buildup of phosphorus.

Phosphate binders are another method you can use to keep your phosphorus level under control. Phosphate binders are medications that help bind extra phosphorus when you eat and can prevent phosphorus buildup. Your doctor will tell you if you need binders and how many you will need to take with your meals. Binders are to be taken as close to your meals as possible, within 15 minutes (either before or after but preferably as soon as you eat). Some examples of phosphate binders include; calcium acetate, renvela and velphoro.

Phosphorus is found in many different foods. Most of the foods that are high in protein or calcium also contain phosphorus. It's nearly impossible to completely cut phosphorus from the diet. The best way to limit

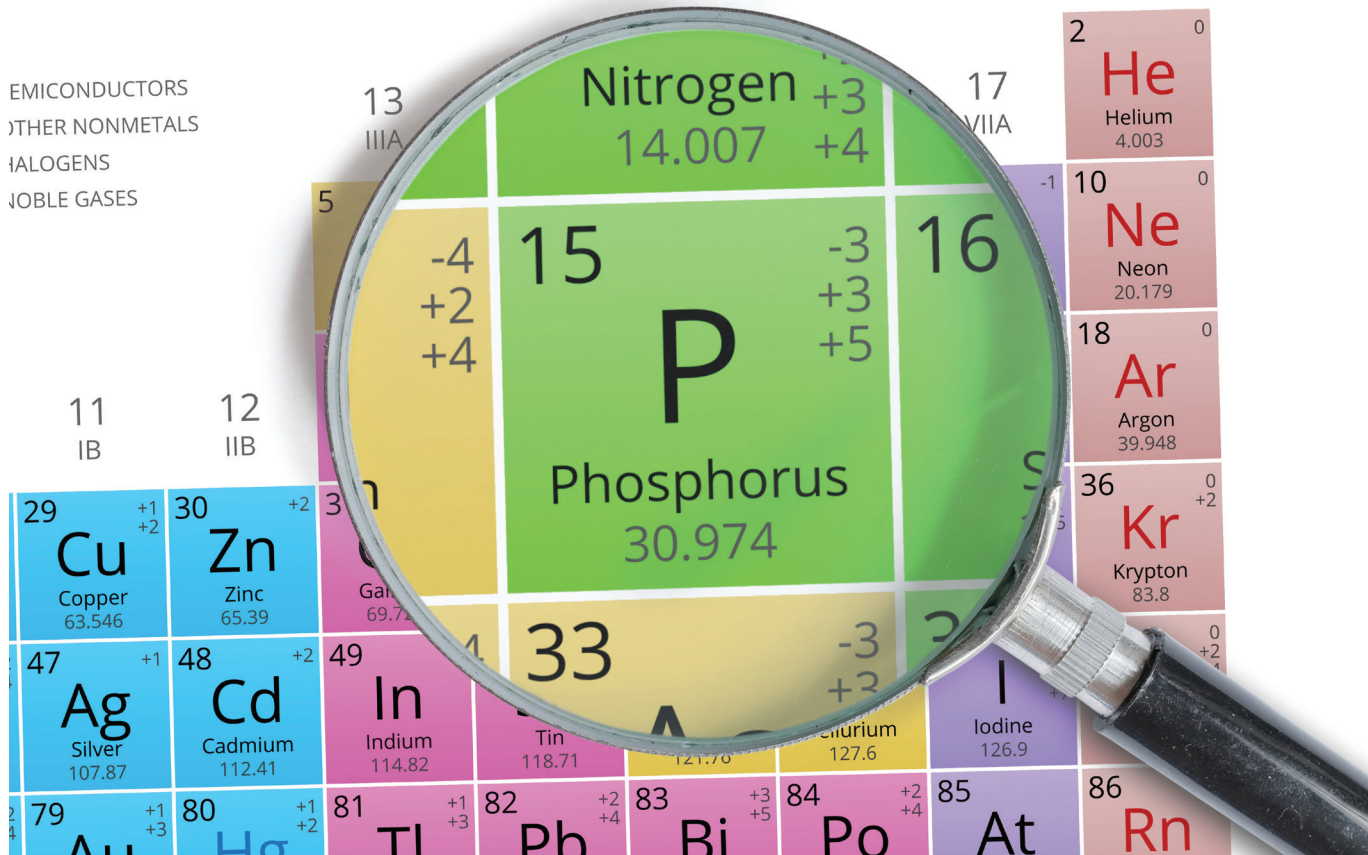
phosphorus in your diet is to limit very high phosphorus foods.

Examples of High Phosphorus Foods;

- Dairy products like milk, cheese, ice cream
- Dark sodas: Coke, Pepsi
- Processed foods: frozen meals, prepackaged foods
- Bacon, hot dogs, sausage, etc.
- Creamy soups and sauces
- Chocolate
- Nuts
- Peanut butter, Almond Butter, Cashew Butter
- Bran Muffins
- Beverages with phosphate additives like Hawaiian punch, some ice teas
- Fast foods

Examples of Low Phosphorus Alternatives;

- Beverages: Zevia products (such as cream sodas), Pure Leaf Ice Tea, Snapple, Fresca, A &W Root Beer



- Processed Meats: Applegate products (lunchmeat, hot dogs, and sausages), Boar's Head Beef Frankfurters, Oscar Meyer Selects: Angus Bun Length Smoked Uncured Angus Beef Franks
- Cheese: Cream cheese
- Milk: Almond milk
- Ice Cream, Sorbet
- Frozen meals with less than 20% phosphorus

Phosphorus can become an issue for people who are on dialysis. Too much phosphorus in the body can lead to life-threatening problems. To avoid phosphorus levels from getting too high make sure you follow a low phosphorus diet, complete all your dialysis treatments/exchanges as prescribed and take your phosphate binders. ■

Low Phosphorus Recipe

Chewy Lemon-Ginger-Coconut Cookies

Yield: 2 dozen cookies (1 serving = 1 cookie)

- Ingredients
- ½ cup unsalted butter (1 stick)
- ½ cup sugar
- 1 egg
- ½ teaspoon baking soda
- 2 tablespoons lemon juice
- 1 tablespoon lemon zest
- 1 tablespoon fresh ginger, peeled and chopped or grated
- 1 ¼ cups flour
- 1 cup toasted coconut (unsweetened)

Directions

1. Preheat oven to 350° F.
2. Spread unsweetened coconut on baking sheet tray, bake until edges are light brown, about 5–10 minutes.
3. Remove from oven and set aside in a bowl.
4. Cream the butter and sugar with electric mixer until light and fluffy. Add egg, lemon juice, chopped ginger and lemon zest and mix until smooth.
5. Sift together flour and baking soda. Stir the flour mixture into the butter mixture and mix until well blended.
6. Cover and chill for at least 30 minutes.
7. Scoop out tablespoon-size balls and roll them in the toasted coconut. Place balls at least 2 inches apart on lightly greased baking sheet tray.
8. Bake for 10–12 minutes until lightly brown on edges. Remove and cool on counter or a cool surface. ■

Source: <https://www.freseniuskidneycare.com/eating-well/recipes/snacks-and-beverages/chewy-lemon-ginger-coconut-cookies>



Nutrition Per Serving

Calories	97 cal
Total Fat	6 g
Saturated Fat	4 g
Trans Fat	0 g
Cholesterol	18 mg
Sodium	40 mg
Carbohydrates	11 g
Protein	1 g
Phosphorus	17 mg
Potassium	27 mg
Dietary Fiber	0.4 g
Calcium	4.4 mg

What's Up With This Support Group Mumbo-Jumbo?

By **Marcy Resnick**, LCSW, Home Therapies Dialysis Social Worker

These days it seems like there is a “support group” for everything and a variety of ways to participate, from virtually (also known as online) or the ‘old-fashioned’ way, face-to-face. Only a small portion of people take advantage of the opportunity to connect with people facing a similar diagnosis—in this case, chronic kidney disease. Why? Some people are understandably uncomfortable discussing their personal lives with strangers. With good support groups, everything discussed within the group should remain confidential. Participating in a support group is just *one more way of giving yourself an edge for living well with a chronic illness.*

People give a number of reasons for not participating

in a support group. Sometimes a person may have tried a support group in the past and had a bad experience. Support groups are dynamic; they change with the mix of people attending and the type of day the participants may have been having —so it might be worth attending a support group more than once before deciding that it is definitely not for you. You may have thought to yourself, “I don’t want to talk about my problems—and I don’t want to hear other people’s problems.” While support groups are not for everyone, you may be surprised by the positive experience you have by meeting with people who are also dealing with a chronic disease and the *hope* it can unlock.

Why do people attend support groups? It gives people





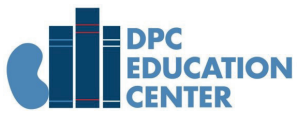
the opportunity to share concerns and experiences with people going through something similar. So, you're thinking, "support groups are good—but for someone else, not me." Well, why not you? Attending a support group has been found to influence better health outcomes or prognoses with some chronic illnesses. A well-run support group provides a safe space for individuals to share their stories, and a place where people identify with a shared experience. There is strength in shared knowledge and understanding. Participating can help give you a sense of power and self-determination. It is a place where you can compare observations about resources, get advice, feel less cut off from others, and maybe even relieve some stress by honestly sharing your feelings.

What exactly is a support group? Often, the term support group is confused with 'group therapy.' Group therapy is a formalized type of therapy led by a mental health professional. Support groups are about *support*, creating a sense of community and connection with a specific focus; it is not formal therapy. A support group can be led by professionals or by non-professional peers.

Every support group is different, so you need to evaluate what type of group you're looking for—structured or informal? Online or in-person? Online support groups allow you to connect with people all over the world 24/7 (any time day or night) and provide a certain amount of an-

onymity. With that, you must also be cautious of the credibility of the people using the group. Beware of people who misrepresent themselves and don't believe everything you read online as truth. Some warning signs that a face-to-face support group or online support group may be the wrong group for you are: fees for attending groups or meetings that are mainly sessions centered around complaining. If you are feeling overwhelmed by attending a support group or discouraged or judged by the group, then the group you are attending is not right for you.

If you are feeling depressed, overwhelmed, or isolated, a support group can help in combination with medical care. If you think sharing your thoughts in a group is something you'd never do, then consider connecting with a counselor to help you find healthy ways to cope with your kidney disease. Support groups or counselors are there to provide emotional support if you're feeling like no one understands your struggles related to kidney disease. Within a group, sometimes humor can be found and it also provides a chance for you to help others who may be struggling with something with which you have struggled. It is your journey but you do not have to go on it alone. If you are interested in starting a support group, you can contact the DPC Education Center for more information on how to get one started or speak with your social worker in your facility. ■



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