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DPC  
EDUCATION  
CENTER

# THE KI<sup>NEY</sup> CITIZEN





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### Dear friends

As I watch the flowers on my patio grow and bloom this summer, I am reminded of how the Dialysis Patient Citizens (DPC) Education Center is growing in both membership and programs. We appreciate your input and feedback as we continuously fulfill the mission of our organization to improve kidney patients' quality of life and to reduce the occurrence of ESRD through education. As we develop new programs and resources, we want to make sure you know about them as soon as possible. So, in this issue of the newsletter, there is a membership postcard for you to complete to ensure that we have your current contact information.

Communication and education go hand-in-hand. We want to learn more about who you are and what you would like to learn more about. We want to share information about our monthly webinars, E-News, updates on public policies, our new Facebook page, our newsletter, and new resources on our web site. You, in turn, can share what topics interest you, ask questions, request copies of resources, and provide feedback to us. Together, we can build a strong community of people committed to our mission of patient empowerment through understanding and knowledge.

Your information and feedback guide us in our desire to meet your needs. For example, last year on our annual membership survey, we learned that you wanted more information on diet and nutrition. This year, we have a monthly recipe posted as a blog on our web site and each of our newsletters has an article on nutritional topics of interest to people with kidney disease. In addition, two of our monthly webinars this year feature a dietitian discussing aspects of traveling while staying on a kidney diet (June) and how to shop for kidney-friendly foods (upcoming in October). Each of our webinars is recorded and available for viewing anytime on our web site. We also address other quality of life topics at your suggestion, such as coping with kidney disease, depression, intimacy and sexuality, and setting goals.

In addition, we will have four issues of our newsletter, the Kidney Citizen this year. We listened when people asked for more articles from people living with kidney disease. Now, in each issue, you will find personal stories and articles written by people who have kidney disease and frequently you will find articles written by caregivers. Our newsletter contains valuable information for those newly diagnosed with kidney disease as well as for those who have been living with ESRD for years. Of course, you are always welcome to let us know what topics you would like to see covered.

I want to assure you that our patient-led organization is active in the global kidney community and will advocate for you, keep you informed, develop new projects and resources, and seek your input as we move forward with our mission's goals. Your membership information will help us to do this. Please complete the enclosed membership form today to help us know more about you and to have a direct way to share with you. I look forward to our continued communication and thank you in advance for your input. ●

Sincerely



Nancy L. Scott  
DPC Education Center  
Board President



# A Future for a Kidney Transplant from Closed Doors: A caregivers' perspective

By **Emily Moore**

I became involved in the kidney community at 8 years of age, when I began helping my mother who had kidney failure from Hemolytic Uremic Syndrome (HUS), a rare disease. I learned from a young age how to set-up and run the NxStage home hemodialysis machine. My mom fought her kidney failure with everything she had. She passed when she was 34 years old, and I was 13 years old.

Lana Schmidt, who knew my mother and me, called me 3 years after my mom passed and invited me to come to a kidney support group meeting and show people how easy it is to set up a home hemodialysis machine. After that, Lana offered me a job being her caregiver, helping her do dialysis in her home. I was thrilled but nervous, since it had been a few years since I had operated or even heard the hum of a dialysis machine. Hearing the familiar heartbeat of the machine, my passion for being a caregiver was ignited once more.

I have been helping Lana for almost 3 years now. The moment I was not prepared for was the moment I had to tell her that she had to stop fighting. The fight was killing her. A dialysis patient has two options when battling his/her disease, to fight or give in. Lana spent 13 years fighting her disease, making the point to not let it get the best of her. She fought me hard in my strong opinion, not wanting to accept

it. She began to develop a bitter attitude, knowing her health was deteriorating.

## **Locked Door**

From the beginning, major transplant centers said it would be difficult for her to find a match. She was not able to undergo desensitization, which removes the antibodies from the blood. Lana had over 100% antibodies from having more than 20 blood transfusions. Against all medical knowledge of her being able to get a kidney transplant, she still believed she would receive a kidney.

## **Searching for the Key**

In April 2013, she met Dr. Benedetti at the University of Illinois transplant center in Chicago, where he said he could help her using an orphan drug soliris/eculizumab that would suppress the antibodies and prevent rejection. He was willing to use a deceased donor as an experimental transplant. The problem was she needed \$110,000 for the drug, knowing Medicare would not cover it because it was not FDA-approved for kidney transplants.

Lana was frantically trying to raise the money and after an exhausting nine-month journey of asking for donations, she knew her time was running out. She decided she would try to contact the head person at the State of Illinois Medicaid

department, soon to find out that Illinois Medicaid had approved the funds for the drug.

### Trying to Turn the Lock

The journey was not over yet, she still needed a kidney with specific criteria. Waiting patiently for a kidney and having high hopes for a phone call, she heard the heartbreaking news that UNOS (United Network for Organ Sharing) had changed their policies. The policy changes resulted in Lana having less of a chance to receive her phone call.

On June 9, 2015, Lana was in a motor vehicle accident, breaking her foot in half. This accident took away more than her ability to walk. It stole her hope. She was not allowed to put any weight on her foot for four months; the transplant was postponed. The healing of her foot was intense and difficult, resulting in her health deteriorating even further.

### Opening the Door



After coming to terms with the state of her health, she let go of fighting and gave in to the circumstances. She told her family and friends that she was exhausted and could not fight anymore. She contacted hospice to discuss options. They came on a Monday, and, on Friday, she received a call that a kidney was waiting for her. Lana surrendered, which is what opened the door for her kidney. She let go of the fight long enough to accept what was happening. On January 30,

2016, she received her kidney transplant. After a long and gruesome fight, she got her long-awaited kidney, and her life has been changed ever since.

Once she received her transplant, it was my time to carry the fight for her. She was exhausted from the stress that her body had been put through. A kidney transplant is not a cure, it does not take away the disease. Lana still experiences fatigue and cannot complete the tasks that healthy people can. I no longer helped her with dialysis, but even though she had the transplant, I had to remember that she was not close to death any longer. When you know that someone is close to passing, there is a distance that you put between the person and yourself; you prepare for the worst. Now that she was no longer close to death, I had to readjust and rid myself of the anxiety of what could happen.

From watching a parent fight this treacherous disease to taking care of someone who had to give up their fight, I have come to the conclusion that being a caregiver is a privilege. Having a disease creates emotional walls inside a person so that they can focus and push hard for what they want and not let others discourage them in their fight. Being a caregiver means you get to come inside of the emotional walls and begin to understand the pain the person is going through. They no longer fake a smile when you ask how they feel, and they are bluntly honest about what they are thinking. You are one of the people they choose to trust and let see what kidney disease has actually done to their mind and body. Whether you want to or not, you are one of the few that can see what kidney disease truly is, and what it takes to overcome the disease.

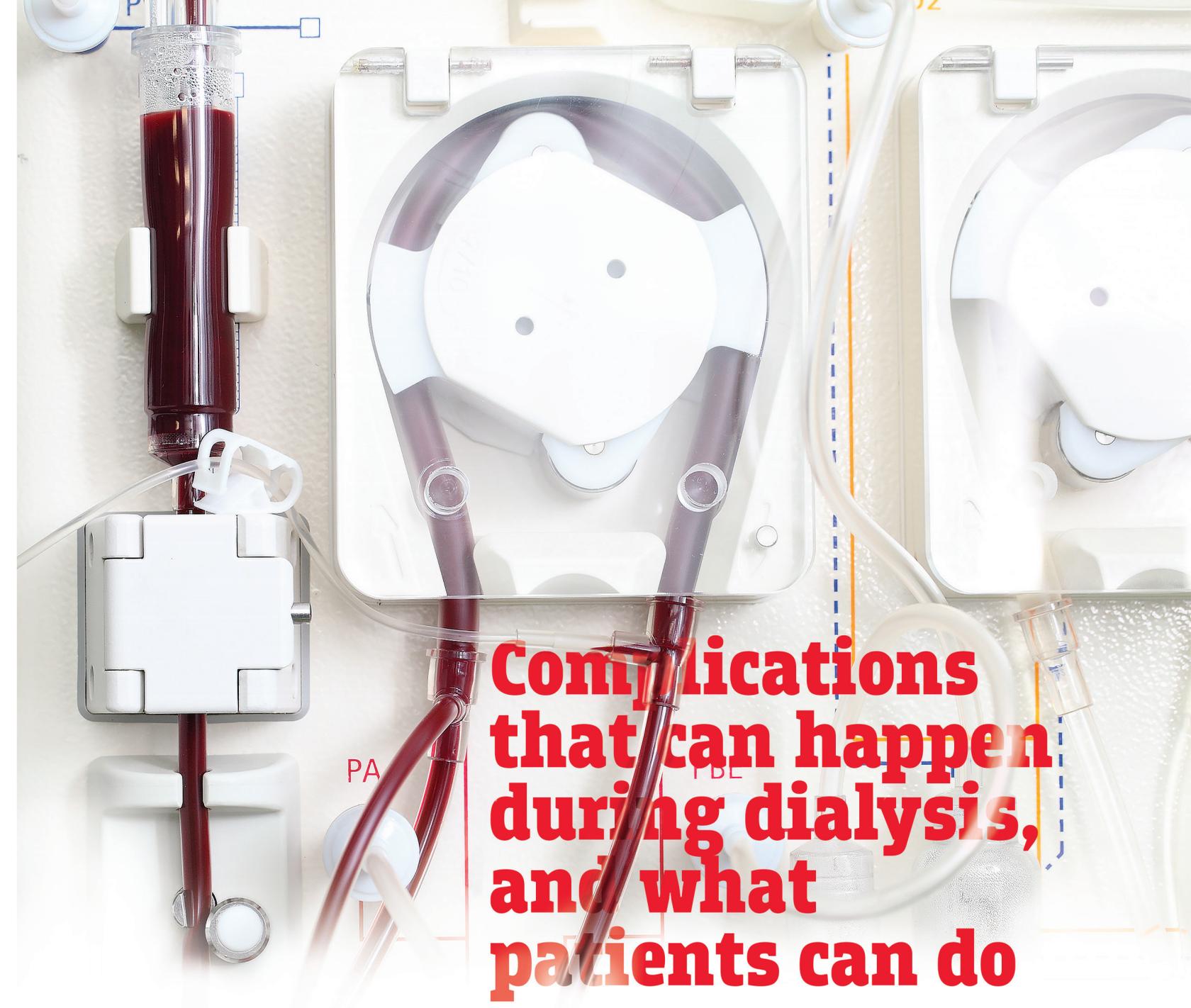
Lana is willing to talk with kidney patients' about dialysis, her journey and the drug that helped her receive a successful kidney transplant. [lanaschmidt10@gmail.com](mailto:lanaschmidt10@gmail.com), [www.lanakidneytransplant.com](http://www.lanakidneytransplant.com)



Emily Moore is studying psychology at John Wood Community College in Quincy, Illinois.

As a kidney patient caregiver for over 7 years she has experience understanding kidney disease and its affect on patients and families.

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# Complications that can happen during dialysis, and what patients can do

(adapted from Diagnosis, Treatment, and Prevention of Hemodialysis Emergencies Manish Saha and Michael Allon)

By **Michael Allon**, M.D.

There are currently approximately 400,000 patients with ESRD on maintenance hemodialysis in the United States. Each one receives dialysis at least three times per week (156 times per year). Given the large number of medical conditions patients on hemodialysis have, and the complexity of the dialysis treatment, it is remarkable how rarely a life-threatening complication occurs during dialysis. The low rate of dialysis emergencies can be attributed to staff vigilance and product innovation.

Most patients will never have or see a dialysis emergency. While it is rare that a serious event could happen during a dialysis session, we outline some of the serious and less serious emergencies that may occur during hemodialysis treatments. If you experience any of these symptoms or see your neighbors experience them, you should alert your dialysis nurse.

Some of the most serious, possibly life-threatening, emergencies include dialysis disequilibrium syndrome,



venous air embolism, venous needle dislodgement, vascular access hemorrhage, or major allergic reactions to the dialyzer or treatment medications.

**Dialysis disequilibrium syndrome (DDS)**

DDS is a rare event occurring when patients with severely high blood urea levels undergo their first dialysis session. DDS symptoms may include headache, restlessness, vomiting, confusion, seizures, and coma. It may be prevented by making the first dialysis session shorter or slower.

**Venous air embolism (VAE)**

VAE results from air being accidentally introduced into the patient’s bloodstream during the dialysis session. If the air goes to the heart or lungs, it may cause chest pain, shortness of breath, or passing out. If air goes to the brain, it may cause blurred vision, confusion, seizures, or stroke. Fortunately, symptomatic air embolism is exceedingly rare during dialysis, thanks to numerous safeguards in the modern dialysis machine.

**Venous needle dislodgement (VND)**

VND is a rare but life-threatening complication of dialysis, in which the needle accidentally slips out of the fistula or graft, causing severe blood loss. The symptoms of severe blood loss include dizziness, confusion, low blood pressure, or passing out. It is important to tape the dialysis needle securely, and keep the dialysis needle clearly visible during the dialysis session.

**Allergic or Allergic-like reactions**

Patients may rarely develop an allergic reaction to the dialysis kidney or to a medication given during dialysis, such as heparin, iron, or antibiotics. Mild cases may cause itching. Severe cases (very rare) may cause swelling of the lips, shortness of breath, wheezing, or low blood pressure. If a patient develops an allergic reaction during dialysis, it is important to determine what they are allergic to, so that the exposure can be avoided in future dialysis sessions.

**Less dangerous complications**

More frequently, patients may develop low blood pressure during dialysis, which could cause dizziness, confusion, or passing out. Low blood pressure during dialysis is usually due to removing too much fluid or removing fluid too quickly. It is treated by giving IV fluids quickly. The dialysis prescription may need to be changed (less fluid removal or slower removal) to prevent low blood pressure during dialysis. Sometimes, it is necessary to make changes in the blood pressure medications.

**Summary**

Thanks to staff vigilance and safety features, serious complications during dialysis are extremely rare. Dialysis staff receive frequent and extensive training in how to prevent these complications, recognize them, and treat them in a timely fashion. ●

# Attitude is Everything

By **Julie Crandall**, DPC Education Center Board member

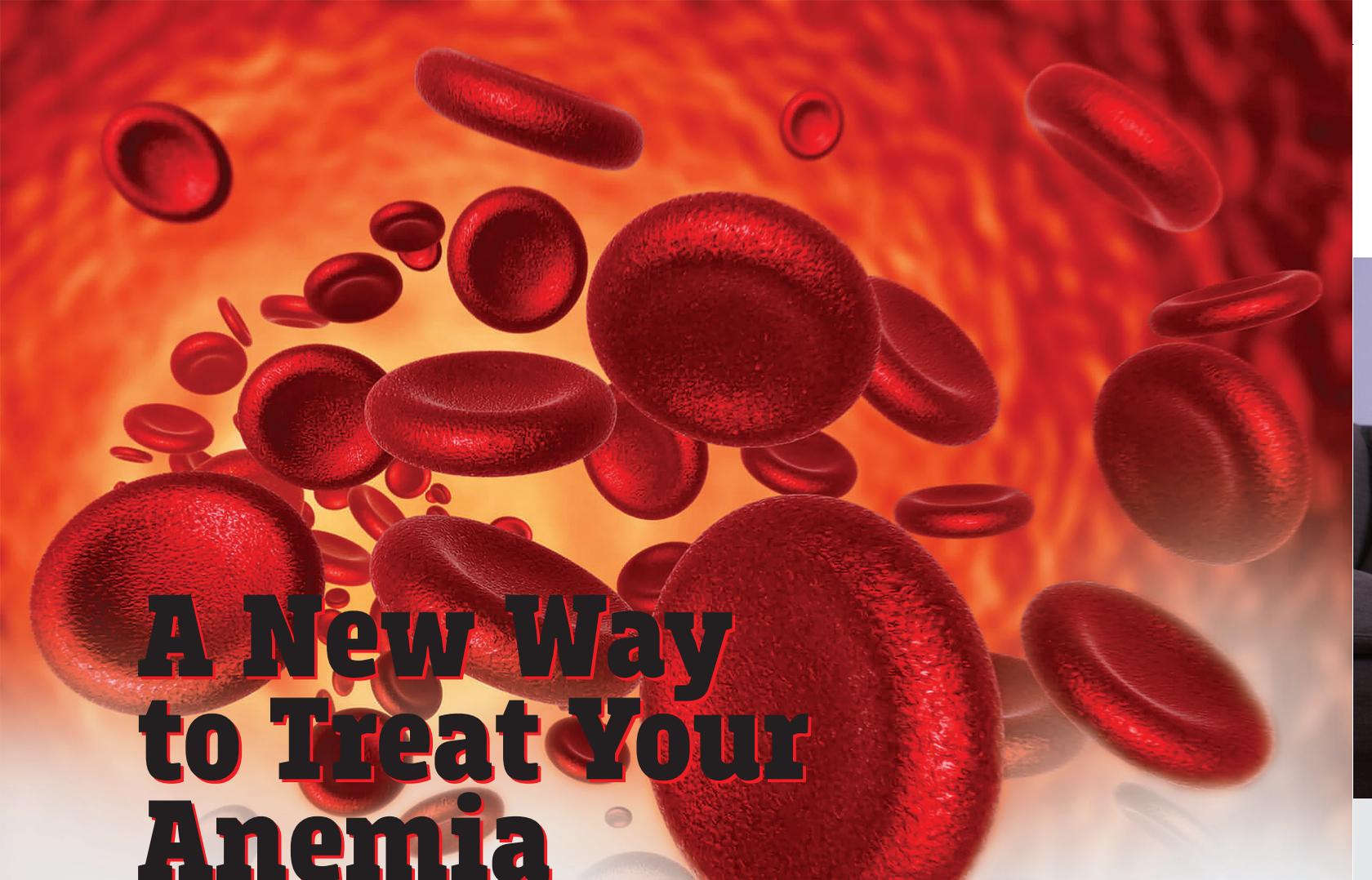
Having 35 years of experience living with kidney disease, I have learned a few lessons. I like to think I was given this life to pass on the things I have learned along the way.

The biggest lesson is that attitude is everything. If you have a positive attitude, it makes living with kidney disease so much better and easier. I started this craziness over 35 years ago, at the age of seven. It was hard to take on so much responsibility; diet restrictions, physical limits, sterility issues, etc. My mom taught me an important lesson I have never forgot. In the beginning, when I would get news of another surgery or another test that had to be done, I would get upset and cry. Keep in mind, I was a kid. My mom would let me cry and have my “pity party”, as we called it, for a few minutes. Then, she would tell me, “OK, now that the pity party is over; now we handle it.” After a while, I would skip the ‘pity party’ part and get right to handling it. What a difference it made. No matter what comes up, I can deal with it without tears or worry.

Another example of having a good attitude in a not-so-good situation is: We have all had the experience of the dialysis nurse or tech having a hard time sticking our access. The

difference is HOW you handle the situation. I learned, it is not worth getting upset over. We can not change the situation. What is the use of getting angry or upset? It makes everybody feel bad, and that takes a lot of energy. The dialysis nurse or tech already feels bad enough. Let us not make them feel worse. Let us say, it is ok, these things happen, relax and take a couple of deep breaths. You can stand up for yourself. You can ask for another staff member to try; or, if you know of a staff member that you trust, ask for that person. Ask calmly and respectfully; people are more likely to listen to you, and work with you.

It is the same with a test or procedure or doctor’s appointment we may have. It is something we need to do, getting upset or angry at the world will just make you miserable. It affects no one else. Then, we will need to go through it anyway. Why make ourselves miserable, when we will need to go through it anyway. I know this is easier said than done. It took me years to come to this realization. All I can do is pass on what I have learned and what works for me. I can tell you that attitude really does make a difference. It makes you feel better overall, and it makes life way more enjoyable... for everyone. ●



# A New Way to Treat Your Anemia

By **Flo Lewis**, R. N. & Unit Director and Kareem Syed Shah, B. COM. B. S. B. A.  
Administrative Manager, Maple Avenue Kidney Center

## **Do you often feel tired, weak and lack overall energy?**

If so, you are likely experiencing a chronic condition called anemia. Dialysis patients suffer from severe anemia because they lose iron at every hemodialysis treatment. This iron loss is from the blood loss that occurs from needle sticks, blood trapped in the blood lines and dialyzer and lab draws, among other things. The bottom line is every time you receive a dialysis treatment, you lose about 5-7 milligrams of iron.

## **Why is iron so important?**

Iron plays an important role in making hemoglobin. It's essential to have enough iron in bone marrow to match the ESA dose to make more healthy red blood cells. Iron+ESA = hemoglobin. Hemoglobin helps carry oxygen from your lungs to all parts of your body and this is how we get energy. So if we are losing iron from the dialysis treatment, it needs to be replaced real time, otherwise we don't get enough oxygen and we lose energy.

## **How can I get my lost iron replaced?**

There are different ways you can get iron:

- Take extra iron pill or liquid by mouth. This has limited

effectiveness for some people due to poor absorption, constipation and nausea.

- Have iron injected directly into your vein or dialysis blood line during your hemodialysis treatment (called "intravenous iron" or "IV iron"). This option should be used if you have excessive blood loss.
- Have your iron replaced during your hemodialysis treatment. This iron is delivered in the dialysate that cleans your blood. It replaces the 5-7 milligrams that you lose so at the end of your treatment your iron balance has been met; you won't even know you are getting it! It also gives your nurse a lot more free time, to provide you with more quality patient care. Unlike IV iron that is injected into your veins or blood line, there are no needles and no awful metallic taste in your mouth.

Talk to your doctor or nurse and ask them to provide the best way to get your iron replaced. Ask for more information on the treatments listed above. You have a choice when it comes to your treatment options and what's best for you. ●

# Receiving Adequate Iron is Essential for My Good Health

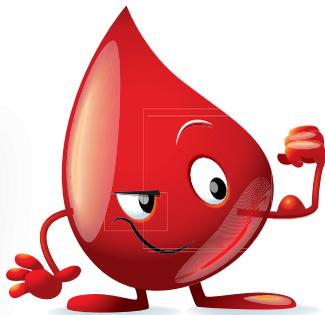


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## IMPORTANT SAFETY INFORMATION

### Warnings and Precautions

Serious hypersensitivity reactions, including anaphylactic-type reactions, some of which have been lifethreatening and fatal, have been reported in patients receiving parenteral iron products. Patients may present with shock, clinically significant hypotension, loss of consciousness, and/or collapse. Monitor patients for signs and symptoms of hypersensitivity during and after hemodialysis until clinically stable. Personnel and therapies should be immediately available for the treatment of serious hypersensitivity reactions. Hypersensitivity reactions have been reported in 1 (0.3%) of 292 patients receiving Triferic® in two randomized clinical trials. Iron status should be determined on pre-dialysis blood samples. Post dialysis serum iron parameters may overestimate serum iron and transferrin saturation.

### Adverse Reactions

The most common adverse reactions ( $\geq 3\%$  and at least 1% greater than placebo) in controlled clinical studies include: headache, peripheral edema, asthenia, AV fistula thrombosis, urinary tract infection, AV fistula site hemorrhage, pyrexia, fatigue, procedural hypotension, muscle spasms, pain in extremity, back pain, and dyspnea.

For full Safety and Prescribing Information please visit [www.triferic.com](http://www.triferic.com).

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Going

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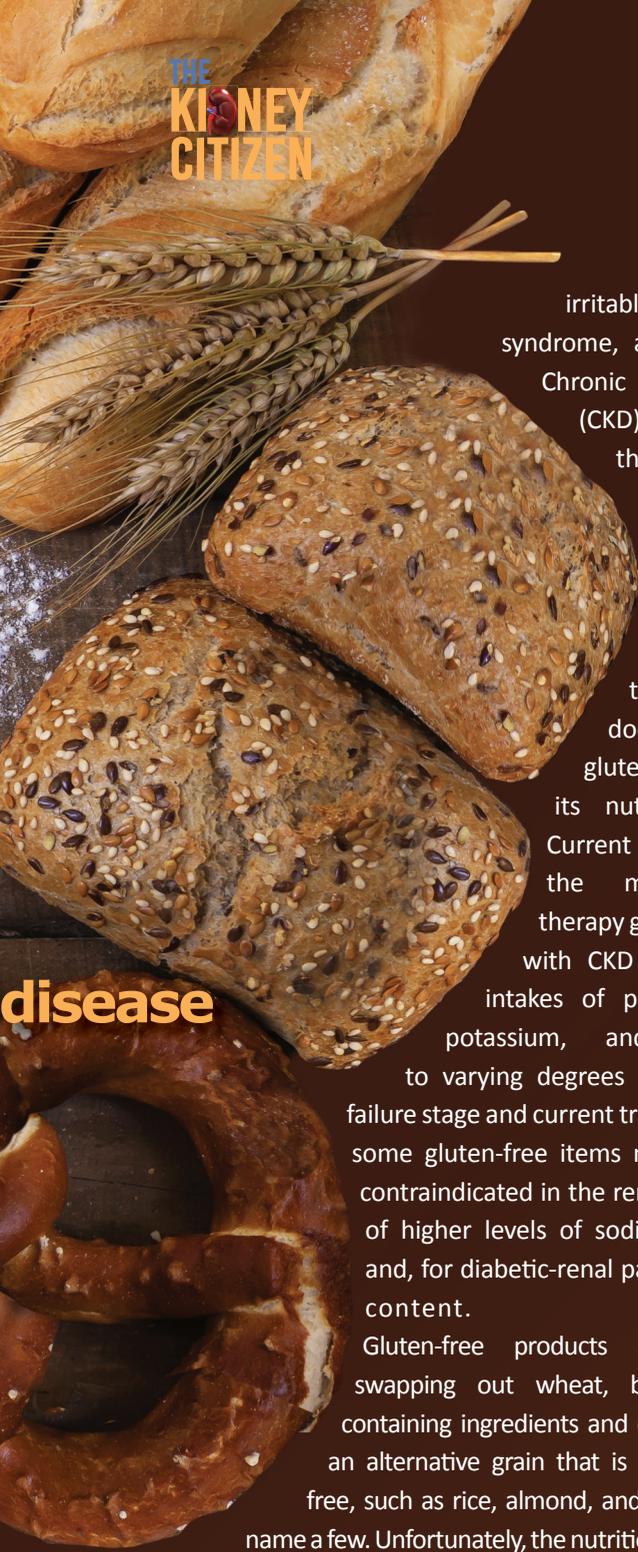
Think twice if you have kidney di

By **Lauren Antle and Jessianna Saville**, R.D., Owner of [kidneygrub.com](http://kidneygrub.com)

By now I am sure you've been to the grocery store and seen a special aisle for all things gluten-free. From gluten-free cookies to gluten-free bread, this label has taken over the supermarket shelves. The gluten-free market explosion begs the questions, "Is gluten free better?" In the minds of consumers, adding the word "-free" to products (for example sugar-free or fat-free) often implies the product is healthier, but this is not always the case, especially for an individual with kidney disease.

So, what is gluten? Gluten is a naturally occurring protein found in wheat, barley, and rye that acts similar to glue in that it helps food maintain its shape (1). Gluten can be found in a variety of foods from bread and pastas to chicken broths and soy sauce (1). Although gluten-free products have been marketed to all consumers, there are very few people who actually need to follow a gluten-free regimen. In fact, the gluten-free diet is currently only indicated for 5 specific medical conditions: celiac disease, wheat allergy, gluten

disease



sensitivity, irritable bowel syndrome, and autism (2).

Chronic Kidney Disease (CKD) did not make the list of medical conditions that require this special diet. This is due to the fact that CKD alone does not use the gluten-free diet for its nutrition therapy.

Current research shows the main nutrition therapy goals for patients with CKD are to control intakes of protein, sodium, potassium, and phosphorus to varying degrees based on renal failure stage and current treatment. In fact, some gluten-free items may actually be contraindicated in the renal diet because of higher levels of sodium, potassium, and, for diabetic-renal patients, its sugar content.

Gluten-free products are made by swapping out wheat, barley, and rye containing ingredients and exchanging it for an alternative grain that is naturally gluten-free, such as rice, almond, and tapioca flour to name a few. Unfortunately, the nutritional composition

of these substitutes varies greatly from all-purpose wheat flour. For example, let us take a look at the nutritional content of wheat flour versus a common alternative in gluten-free cooking. One-fourth cup of all-purpose wheat flour contains 33.75 mg of phosphorus and 33.44 mg of potassium, whereas one-fourth cup of almond flour contains 131.96 mg phosphorus and 204 mg of potassium. Although the idea of switching flours is to make food comparable, it is important to note that the nutritional content can vary. Some gluten-free grains are comparable while others are not.

To compare gluten-free products in terms of the renal diet, let us look at the nutritional makeup of common products.

One Thomas™ Original English muffin contains 210 mg of sodium, whereas a gluten-free English muffin from Glutino™ contains 440 mgs of sodium. The amount of sodium is more than doubled in the gluten-free product compared the wheat flour product. A similar conclusion is made when looking at frozen waffles. A serving of Kellogg's™ Cinnamon Toast Waffles contains 270 mgs sodium, whereas a serving of Kashi™ Gluten Free Cinnamon Waffles contains 482 mg of sodium. This same trend is noticeable in other gluten-free products as well (see table below).

PRODUCT	SODIUM CONTENT (MG)
Nature's Own™ Light Honey Wheat Bread (1 slice)	125
Rudi's Gluten-Free Bakery™ Sandwich Bread (1 slice)	190
Chips Ahoy!™ Original Chocolate Chip Cookies (1 serving = 3 cookies)	110
Tate's Bake Shop™ Gluten Free Chocolate Chip Cookies (1 serving = 2 cookies)	135

Sodium is one of the only nutrients that, if reduced, can help prevent further progression of CKD (3) and, therefore, this nutrient is very important to look at when reading nutrition labels. If you are not suffering from a condition that requires the gluten-free diet, there is no reason to consume the additional sodium when you could have the same product that tastes better and is better for your kidneys.

Although the gluten-free diet can be helpful for those suffering celiac disease or gluten sensitivity, eating more of these products may increase consumption of sodium, which can further progress renal function loss or contribute to difficulty controlling fluids for dialysis patients. As someone with CKD, it is important to take all measures possible to delay progression and prevent/treat complications (3). The gluten-free diet does not aim to accomplish these goals and could end up further damaging the kidneys if caution is not taken while consuming these products.

For individuals with kidney disease needing a gluten-free diet, or for those interested in cutting gluten out of their diet there are some things you can do. First, watch your labels closely for potassium and sodium content of food. If diabetic, be especially careful of carbohydrate content as some gluten-free products have a large amount of added sugars. Some gluten-free products can be good choices for kidney patients such as Bob's Red Mill™ Pancake Mix (x mg K<sub>+</sub>, x mg Sodium). Other great products could be unsalted rice crackers (ex: Edward and Sons™ Brown Rice Snaps). Watch out for products made with large amounts of oat flour, oat bran, and/or almond flour. A gluten-free kidney



diet would have rice and corn as its base carbohydrate with meals, with moderate amounts of whole oats. For example, it could include Rice Krispies or Corn Chex for breakfast with rice milk, corn tortillas (without phosphorus additive) with meat and vegetables for lunch, and rice with fish plus

your favorite low potassium vegetable for dinner. Another less known grain you could use would be millet.

In conclusion, following a gluten-free diet is do-able with renal failure patients with proper attention paid to ingredients. Reading the ingredients is very helpful to know which alternative grains the product is using and gives a better understanding of the nutrition content. As stated before, products made with large amounts of grains that are higher in potassium, phosphorus, and sodium should be limited. Potassium and sodium are on most nutrition facts and will aid in finding products that are appropriate for the renal diet. The table below will be helpful to grow your knowledge base on the common ingredients. The gluten-free diet is not part of the nutrition therapy for CKD patients; however, if you suffer from a condition that requires a gluten-free diet, the two can absolutely co-exist with some caution and research. ●



Alternative Grain (1/4 cup)	Calories	Protein (g)	Phosphorus (mg)	Potassium (mg)	Sodium (mg)
White Flour	113	3	33.75	33.4	0.63
Whole Wheat Flour	102	4	107	108	0.6
Wheat Bran	57.75	4	147	133	1
Brown Rice Flour	143	3	133	114	3.16
White Rice Flour	145	2.35	38.71	30.02	0
Almond Flour	160	5.84	131.96	204	2.99
Potato Starch Flour	160	0	N/A	25	0
Potato Flour	143	2.76	67.2	400	22
Tapioca Flour	85	0	0	2.5	0
Cornstarch	122	0.08	4.16	0.96	2.88
Xanthan Gum	120	0	0	0	800
Sorghum Flour	109	2.55	84.1	98.01	0.91
Oat Bran	57	4.07	172.49	133.01	0.94
Oat Flour	113	4	123	108	1.8
Millet	189	5.5	142.5	97.5	2.5



Products	Calories	Protein (g)	Phosphorus (mg)	Potassium (mg)	Sodium (mg)
Ezekiel™ Low Sodium Bread (1 slice)	80	4	79.9	80	75
Rudi's™ GF Original Sandwich Bread	110	<1	12.58	31.28	190
Chips Ahoy!™ Original (3 Cookies)	160	2	25	45	110
Tate's GF™ Chocolate Chip Cookies (2)	140	1	N/A	N/A	135
Glutino™ GF English Muffins (1 muffin)	170	4	N/A	N/A	440
Bob's Red Mill™ GF Baking Flour	130	2	19.77	23.82	10
Kashi™ GF Cinnamon Waffles (2 waffles)	160	3	N/A	40	270
Kellogg's™ Cinnamon Toast Waffle (3 waffles)	300	5	254	70	482
Stauffer's™ Animal Crackers	126	2	21	28	115
Simple Truth™ GF Animal Crackers	120	2	N/A	0	70

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# The Importance of Charitable Assistance

By **Megan Beveridge**, Director of Congressional Relations, Dialysis Patient Citizens

Many people are under the impression there is no bipartisan cooperation right now in Congress – and especially on health care issues. However, that is not necessarily the case. Towards the end of May, and after encouragement from Dialysis Patient Citizens (DPC) and other kidney groups, over 150 bipartisan Members of Congress signed onto a letter to Secretary Price urging him to protect non-profit charities' ability to provide charitable assistance to kidney and other chronic disease patients. For decades, non-profit organizations have provided premium and cost sharing assistance for patients who struggle to afford staggering health care costs. This safety net has helped thousands of families each year avoid sacrificing their way of life and life savings because of medical circumstance. Currently, more than 678,000 Americans are living with kidney failure, which is known as End Stage Renal Disease (ESRD). Of these, approximately 477,000 require life-sustaining dialysis

treatments three times a week to replace the kidney function they have lost. These treatments are time consuming and very costly so being able to use premium assistance through the American Kidney Fund is literally life-changing.



For background, in December, the Obama Administration issued an Interim Final Rule (IFR) that would have allowed insurance companies to deny patients who were paying their premiums with charitable assistance – they basically could have discriminated against kidney disease patients and refused to cover them. Because of the harmful and disproportionate

impact this would have had on kidney disease patients, DPC filed a lawsuit to block this rule in the U.S. District Court for the Eastern District of Texas – and we won. In the ruling, the Court found that “Congress has long recognized the importance of dialysis treatment for ESRD patients and has afforded patients the opportunity to elect coverage that best



serves their needs. For decades, ESRD patients have had the choice of selecting private insurance options over Medicare if those options better served their treatment needs. Private insurance is particularly attractive to ESRD patients with families because Medicare does not provide coverage for spouses and dependents.” We here at DPC agreed with this ruling. We are glad so many House of Representatives Members did as well and signed on to the charitable assistance letter. But this does not mean our work to protect kidney disease

patients is over. The Senate will likely consider health reform proposals in the coming months, and in anticipation of this, Senator Hatch, Chairman of the Senate Finance Committee, sent out a request for information to stakeholders in the health care field. DPC was happy to respond and stress not only the importance of the need to protect charitable assistance, but also the need to clarify language from the American Health Care Act (AHCA) to preserve coverage choices for individuals with ESRD by confirming their eligibility for tax credits to obtain private coverage.

Kidney disease patients, like all other patients, should be able to elect coverage that best meets their needs, whether that be public or private coverage, and through access to charitable assistance they are able to do just that. We look forward to continuing to work in a bipartisan manner with Congress to ensure this very vulnerable patient population continues to have access to affordable, quality health care. ●



# Airports, dialysis units and mindfulness

By **Gary Petingola** B.S.W., M.S.W., R.S.W.\*

Mindfulness on the Rocks – Meditation Solutions for Maximum Life Impact

**Sudbury, ON, CANADA**

Airports are both happy and sad places. They play havoc with all of our emotions. Hellos, goodbyes. Gut wrenching sadness, extraordinary joy. Conflict, impatience, judgment, anger. Airports represent pivotal transitional points that mark either the end of a journey or the beginning. They are places where hours and hours of time pass just sitting, held captive.

Airports are filled with lovers embracing, exchanging hellos and goodbyes. They are filled with families bidding farewell

to children, parents and relatives. They are filled with lonely individuals enthralled by their mobile phone conversations and with workers who sometimes struggle to smile. It is all there if you simply open your eyes and look.

Dialysis units can be like airports. We arrive and depart trying to get somewhere else. We carry excess baggage that we divest ourselves of or cling to. Dialysis units are busy places where visitors simply go through the motions. They can be places of joy or places of suffering. At times staff can appear to be grumpy and indifferent like staff at airports, overextended, removed, and tired.

Similar to airports, dialysis units necessitate prolonged sitting, dead time, and endless unpredictability. Like airports, dialysis units can be viewed as temporary interruptions along the path of life. We can navigate through them on autopilot, blindly or we can breathe and perhaps even smile along the way.

Mindfulness offers us that choice. Mindfulness is paying attention purposefully, in a particular way without judgment. Both airports and dialysis units offer us potential peak moments. Peak moments are times in your life when you are completely present with all of your senses, acutely and luminously. When you see children at airports they scan curiously, paying close attention to the details that the rest of us miss. We can choose to simply become an extension of the dialysis machine, programmed, mechanical, and just existing, or we can choose to accept what is, and, in doing so, make this stop-over a place of exploration and spaciousness.

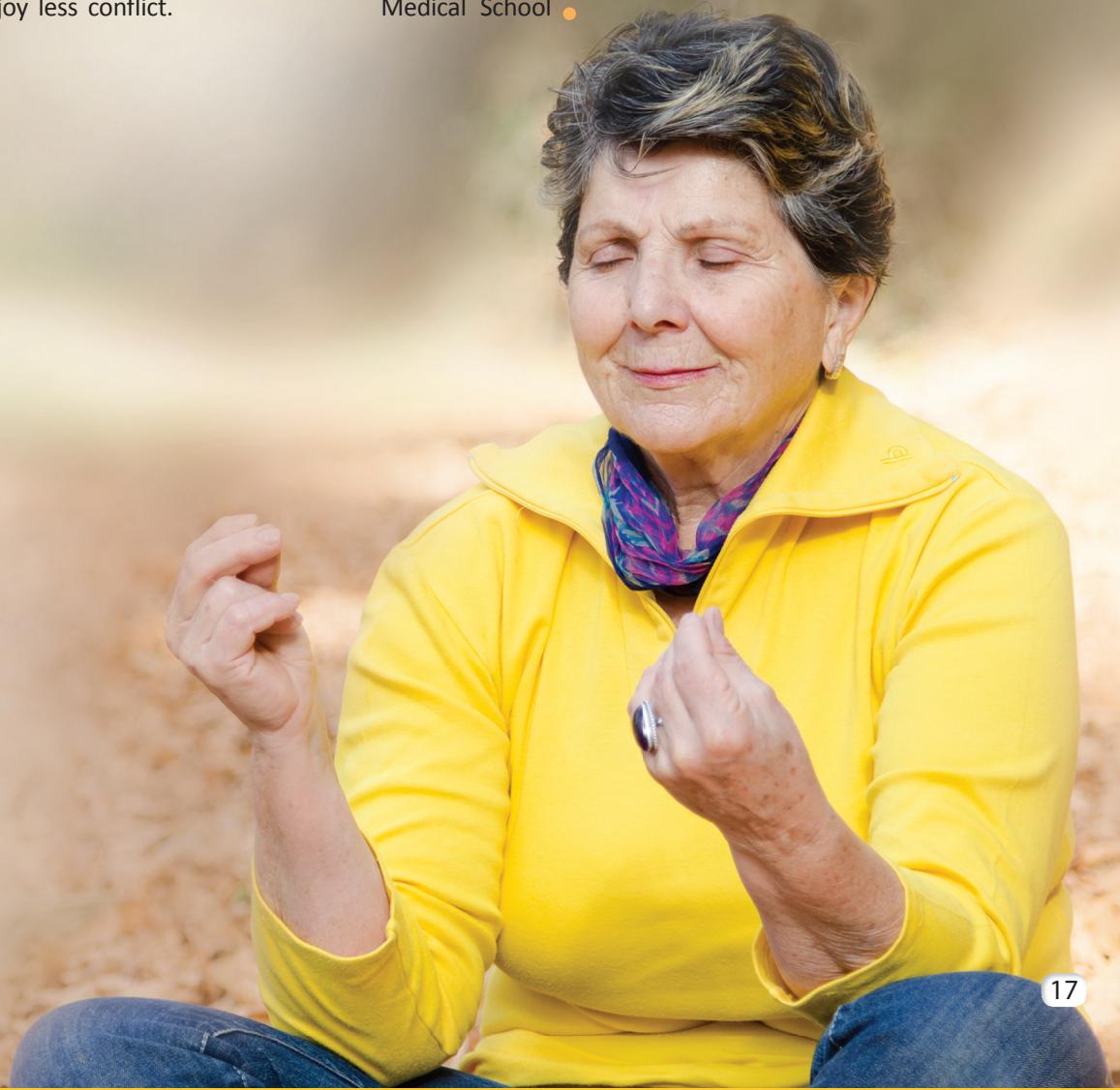
When we try to escape our current circumstances we suffer. This “running from” makes us sick emotionally and physically. It churns in us like an undercurrent, always there, always taking our energy. When we are mindful, we feel more calm. We see more clearly. We listen and speak with true presence, and we enjoy less conflict.

The practice of mindfulness through meditation helps us to cultivate this innate opportunity to see the world differently. It offers us beginners eyes so that we can explore fully what is. We spend so much of our life on hold or in fast mode always striving to be somewhere else. We seek distraction in an effort to find happiness but continue to feel unfulfilled. Consequently, we miss what is most important - this moment.

When we are mindful we are fully awake. We are in tune with our bodies, our thoughts and our emotions, the pleasant, neutral and the unpleasant. This clarity makes us feel alive. It helps us to truly see what is.

Mindfulness allows us to feel more deeply, love more passionately, and continue more completely. These abilities distinguish us from the machines of airports and dialysis units and make us more resilient. Mindfulness frees us from captivity and the doldrums of living in auto pilot allowing us to simply be.

\* Qualified to teach Mindfulness-Based Stress Reduction through the Center for Mindfulness in Medicine, Health Care, and Society at the University of Massachusetts Medical School ●





# Won't You Stay Just a Little Bit Longer?

By [Lisa Hall](#), M.S.S.W., L.I.C.S.W. and the ESRD Network 16's Patient Advisory Council

Do you ever get tired of hearing from your dialysis staff that every minute you cut from your dialysis time adds up to minutes off your life span? The Northwest Renal Network (ESRD Network 16) Patient Advisory Committee (PAC) was also weary of this approach to patient education about 'adherence' and decided to do something about it. People are more motivated by rewards they will reap by taking care of themselves than by the consequences of not taking care of themselves. Instead of what will happen to you if you do not stay, the PAC did some research on incentives to stay for the full prescribed dialysis treatment. They then developed a poster 12 Good Reasons to stay through a Full Treatment.

**Why stay?** Here is Network 16's PAC list. Can you think of some other reasons?

Stronger bones	Healthier teeth
Better sleep	Less swelling
Quality of life	Healthier skin
More energy	Better appetite
Cleaner blood	Less itching
Fewer hospital visits	Transplant eligibility



The PAC also agreed that sitting in a dialysis chair for 4 hours, 3 days per week is hard! They came up with the list below of things to do to pass the time on dialysis. Can you think of other creative ways to pass time on dialysis? ●

<b>Passing the Time While on Dialysis</b>	
<b>Share renal diet recipes and tips with peers</b>	<b>Watch television</b>
<b>Read books or magazines</b>	<b>Write in a personal journal</b>
<b>Do crossword puzzles or other word games</b>	<b>Work on a laptop</b>
<b>Use an iPad, smartphone, or laptop for responding to emails, playing games, reading, viewing movies or YouTube, Skyping with friends, and socializing on Facebook</b>	<b>Listen to music, audio meditation CDs, books, or podcasts</b>
<b>Use a Tablet with ear phones</b>	<b>Learn a new language</b>
<b>Watch movies on a portable DVD player</b>	<b>Sketch</b>
<b>Chat with other patients</b>	<b>Say daily prayers</b>
<b>Crochet or knit</b>	<b>Nap</b>
<b>Take a college class online</b>	<b>Pay bills</b>
<b>Plan vacations</b>	<b>Daydream</b>



**Won't you stay? Just a little bit longer?**

More from Network 16's PAC members:

"I care about myself and want the best for me. There are only good things for me if I stay for my full treatment."

"I am motivated to stay for my full treatments as I choose to live a quality life. There are times when staying is very difficult. However, the alternative is so much worse. I know to challenge myself for the best outcome."

"I want to thrive, not just survive, on treatment."

"My children were teenagers when I started dialysis. It was very important to me to be healthy so they would have a mom who could support them. It was my job. Now they are in their 30s."

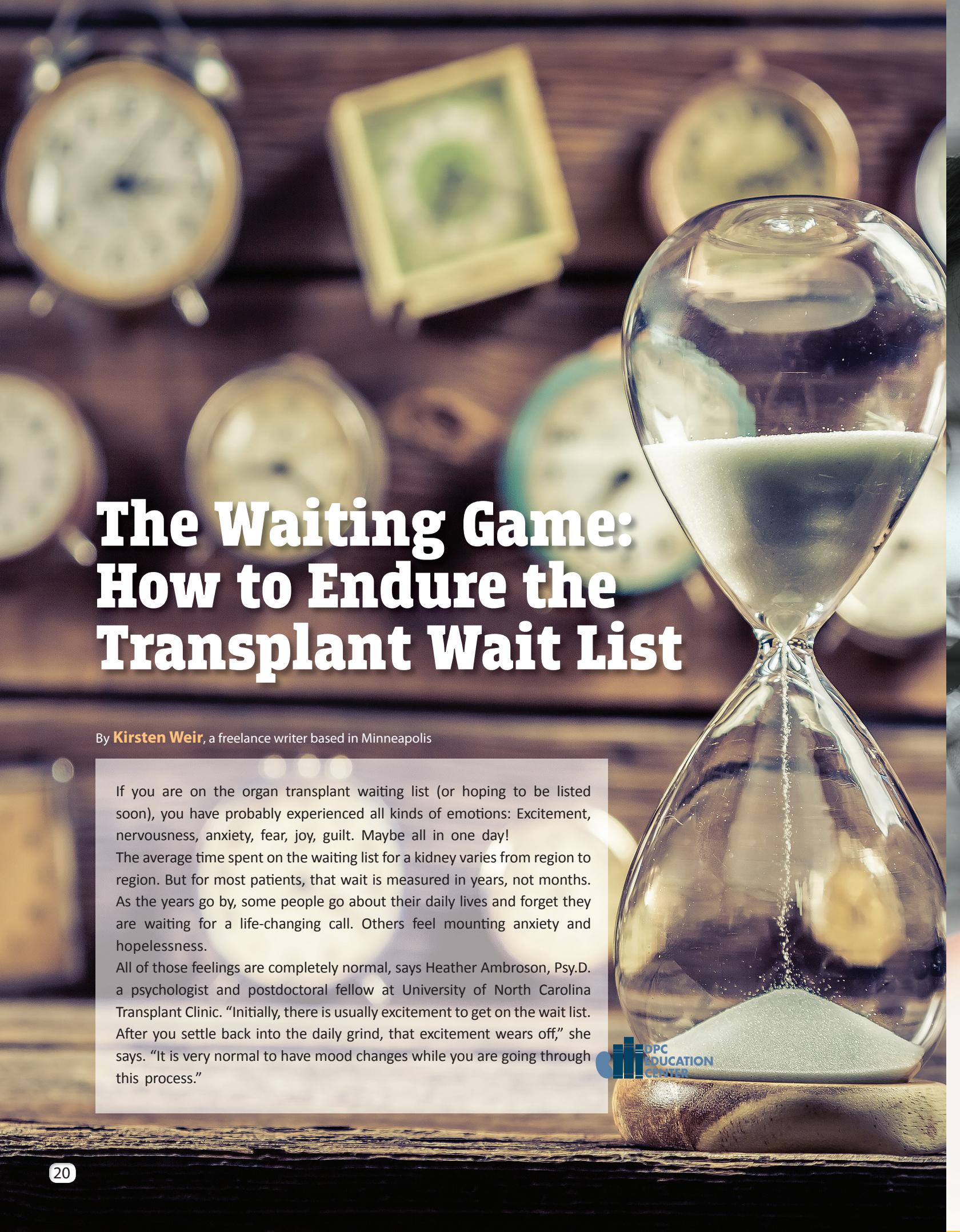
"Knowingly shortening my life is not an option. I choose to stay for treatments as I choose to live."

"The people who love you want you to be well too. You're an important part of their lives."

"I want to live as well as I can for as long as I can. Every minute on dialysis is another minute longer of life: another minute to love, another minute to laugh, and another minute to make a difference. It's worth it to me."

"Your life is what you make of it – do what you can to make it last."

Ms. Hall is the Patient Services Director at HealthInsight ESRD Network 16.



# The Waiting Game: How to Endure the Transplant Wait List

By **Kirsten Weir**, a freelance writer based in Minneapolis

If you are on the organ transplant waiting list (or hoping to be listed soon), you have probably experienced all kinds of emotions: Excitement, nervousness, anxiety, fear, joy, guilt. Maybe all in one day!

The average time spent on the waiting list for a kidney varies from region to region. But for most patients, that wait is measured in years, not months. As the years go by, some people go about their daily lives and forget they are waiting for a life-changing call. Others feel mounting anxiety and hopelessness.

All of those feelings are completely normal, says Heather Ambrosio, Psy.D. a psychologist and postdoctoral fellow at University of North Carolina Transplant Clinic. “Initially, there is usually excitement to get on the wait list. After you settle back into the daily grind, that excitement wears off,” she says. “It is very normal to have mood changes while you are going through this process.”





The good news is that there are steps you can take to make the wait a little less stressful.

Don not hide your feelings. Many people on the transplant list put on a brave face, even if they are struggling inside. Some are even afraid to tell their providers what they are feeling, for fear it will hurt their chances of receiving an organ. "Some people think they might be taken off the wait list if they are feeling depressed or anxious, because their doctors will think they are not a good candidate," Ambrosion says. "But that is not the case." Ask for professional help. Most dialysis centers and transplant centers have trained psychologists and/or social workers on staff. They can help you navigate the turbulent emotions that go along with the uncertainty of waiting. If such an expert is not readily available, chances are your doctor can recommend one in your community. Talk to people who have been through it. It can be a relief to connect with another person who has walked in your shoes. Look for support groups at your transplant center, or ask your doctor if he or she can put you in touch with a former patient.



Many transplant centers have mentorship programs that pair post-transplant patients with those who are waiting for an organ.

Help your family help you. Your family and friends might be extremely helpful, or they might not realize how much you need. Wherever they fall on that spectrum, it is less frustrating for everyone if you learn to be upfront about how they can help. “A lot of patients do not like to ask for help. They might already feel like a burden,” Ambrosion says. If you are clear and honest about what you need, everyone is likely to be less frustrated.

It is also a good idea to bring family members to your transplant appointments so they have realistic expectations. Hearing it directly from your medical team can help family members better understand what you can and can’t do. “If your family is educated about the transplant process, it is better for everybody,” says Kristin Kuntz, Ph. D., a transplant psychologist at The Ohio State University Wexner Medical Center.

Reset your expectations. While you wait for a kidney transplant, your health may decline. You might not be able to do the everyday tasks that you used to do. That can take a toll on your mood and your self-esteem. “You have to be willing to change your expectations about what you

physically can or can not do,” Ambrosion says.

Try setting new, smaller goals for things to achieve each day. You might not be able to go for a jog, but you can set a goal of taking a 10-minute walk. “Be gentle with yourself. You might have to find a temporary new normal while you are going through this,” Ambrosion adds.

Take control. When you are living on dialysis and waiting for a transplant, life can feel full of uncertainty. Regain control by focusing on the things within your power. You can determine what you eat, how often you are physically active, and whether you take your medications. You can also prepare your home for post-surgery. Make sure you have supplies you will need, like a pill box, a blood pressure cuff, and a notebook to record medical information. “Focus on what you can do instead of worrying about the things that are out of your hands,” Kuntz says.

Focusing on the things you can control will help you feel calmer now, and ensure things go more smoothly in the future, Ambrosion adds. “Anything you can do to take care of yourself during the wait list process will help you after the transplant,” she says. “The better your physical condition, the more prepared you are, and the more support and coping skills you have going into the surgery, the better you will recover.” ●



# Patients Share Their Stories Through Kidney Patient Views Podcasts

By **Quin Taylor**, Patient Liaison

## The Renal Network-ESRD Network 10

You can type anything into Google and find a million answers to a million questions. Technology helps us get information quickly and endless devices put this information right at our fingertips.

Imagine being a kidney patient and being able to hear the real life stories and experiences of others? With just a few taps, hearing people talk about situations and feelings that you can relate to firsthand? With the podcast series Kidney Patient Views – Real Stories from Real People, this information is as close as your smartphone, tablet, or laptop. I have had the good fortune to facilitate the podcasts and share honest conversations with people who are relatable and sincere. As a renal patient, I understand the impact of hearing directly from others who live in similar situations. There are currently seven episodes in the series, but the list is growing each month. I have found no shortage of people who are happy to share their experiences, good and bad, with me. The series can be found by searching iTunes, Google Music



Play and they are also available at the Network's website, <http://www.therenalnetwork.org/Resources/podcasts.html>.

Current topics include:

- **Episode 6:** A Transplant Recipient Gives Back as Home Therapy Nurse
  - **Episode 5:** A Living Donor Transplant Story
  - **Episode 4:** Quin's Transplant Story
  - **Episode 3:** Robert Felter Award Winner Talks About his Work in the Kidney Community
  - **Episode 2:** Emergency Preparedness
  - **Episode 1:** Home Dialysis – Nothing to Fear
- This podcast series educates patients about being on dialysis while giving them a window into what dialysis is and can be. We want patients to be empowered by stories from others who have overcome hard situations. We want them to be encouraged by stories of people and their selfless will to help dialysis patients. We also want them to feel supported as others share their personal stories and journeys to dialysis acceptance. If you are interested in more information, please feel free to contact me at [Qtaylor@nw10.esrd.net](mailto:Qtaylor@nw10.esrd.net). ●



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