

National Kidney FoundationTM kidney living[®]

Spring 2014

TRANSPLA EXPLORING THE OPTIONS

LET'S TALK

STARTING YOUR OWN

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Issue 6

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kidney living[®]

A MAGAZINE FOR PEOPLE ON DIALYSIS

Celebrate Health

Sometimes I find it hard to believe this year I will celebrate my 20th "kidney birthday." It has definitely not been a smooth ride, life typically never is, but when you add in kidney disease, years of dialysis, and transplant, it proves to be a little bit bumpier.

I won't forget that day, at age 15, being told I'd need a kidney and would probably be on dialysis. What a foreign concept for most of us, but as a teenager, it was a whole other ballgame. While juggling college and hemodialysis, I went to classes, enjoyed football games, and hung out with friends. Crazy as it sounds, I even worked as a dialysis technician!

Even now, I try to keep involved in activities (with a little help from my 4 kids). I enjoy teaching them my love of music, Legos, and penguins. I am constantly reminded of the blessings given to me — my wonderful family and winding career path. It all goes to show the importance of maintaining hobbies and taking time for YOURSELF.

In this issue, we will highlight transplantation as a treatment option. However, no matter what treatment you choose, we'll share ways to keep yourself active and involved. It's not always the easiest thing to do, but whatever you can do will help make your treatments part of your life, not the center of your life.



Mark Conard

Mark Conard

Psychologist, Transplant Recipient, Former Dialysis Patient and Dialysis Technician

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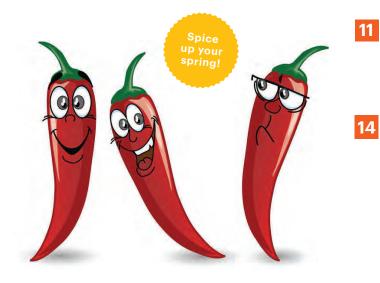
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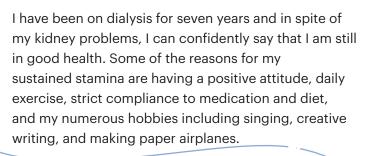
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Inspiring Others... 4

inspiring OTHERS

Being a dialysis patient is not easy, but I find many ways to stay positive and take time for myself!

By Peter SJ. Advento, Jr.



In addition, I am blessed with a wonderful family and friends who surround me with positive energy. Although I get frustrated with my dialysis treatment at times, I always treat everyone with respect.

I make an effort to talk with everyone I meet because you can always learn something new. I talk with my driver who transports me to dialysis. In the lobby, I communicate with fellow patients. Sometimes it takes a little while to be connected to the machine so there is plenty of time to engage in conversation. During treatment, I talk with the patients next to me and also with the staff. I am very lucky to have a wonderful dialysis care team; kindness flows deep in their hearts.

In addition to surrounding myself with positive energy, I also take time for myself. I practice yoga daily in the morning and at night. I find it keeps me relaxed and strengthens my body and my mind. I also make sure to get a good night's sleep!

I also take my medications as prescribed. I keep my monthly lab results in the same place so that I can monitor changes over time and have all the paperwork handy when I need to refer to it. I find this is very helpful in determining how my potassium, phosphorus, and calcium levels fluctuate based upon my diet.

I was not able to continue working after starting dialysis and so my hobbies have become an important part of my life and my identity. Part of my healing therapy is singing my heart out. I am part of a senior singing group that meets weekly. Singing also helps to brighten others' day, which helps me feel happy.

I'm also a member of a creative writing group, which is a great source of inspiration. I am the only guy in the group, but they have welcomed me with open arms. This has been a great way to express myself, use my imagination and explore new ideas.

Lastly, making toy paper airplanes and helicopters has become my passion. Usually I give them as gifts to my friends and family. I've learned you're never too old to learn something new!

TINY TECHNOLOGY MAY EVENTUALLY LEAD TO

ADVANCES

What image comes to mind when you hear the word nanotechnology? Perhaps you think of a science fiction movie involving millions of tiny robots rapidly building or taking apart a large object.

NANOTECHNOLOGY can

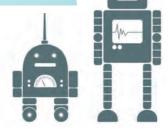
be defined as the science of manipulating materials on an atomic or molecular scale, especially to build microscopic devices such as robots.

How is this science important to those with kidney disease? A recent editorial in the National Kidney Foundation's journal, *Advances in Chronic Kidney Disease*, by Dr. Jerry Yee, discussed some of the interesting technological advances that are being made in the field of nephrology.

One exciting new development involves the wearable artificial kidney (WAK). Models of these tiny dialysis devices (less than 10 lbs) are currently being studied. The idea is that these devices would be worn 24 hours a day and provide blood filtering similar to, or better than, any of the other hemodialysis techniques.

Another example of "smaller can be better" is the creation of blood sensors that can fit in the blood lines of dialysis machines and provide instant feedback on levels of calcium, phosphorus and glucose. This would allow for adjustments in dialysis that would make it safer and more effective.

If we want to get truly nanosized, there is interesting work being done on filters that are small enough to remove even the smallest germs from dialysate, such as viruses and bacteria. These



filters could selectively remove toxins from the blood.

Other researchers are looking at making slight changes in cell genes to turn off their "bad behavior." For example, these changes could block immune cells in diseases such as lupus and certain types of kidney diseases that are caused by an overactive immune response.

Thinking small can lead to big things when it comes to science and medicine! There may come a time when an army of tiny robots can repair our kidneys, but in the meantime, let's just appreciate the small things in life.

LET'S TALK TRANSPLANT!

When a person's kidneys fail, there are two types of treatment available: dialysis and kidney transplant. There are benefits and drawbacks to each type of treatment. In this issue of *Kidney Living*, we'll explore the option of kidney transplant.

WHAT IS A KIDNEY TRANSPLANT?

A kidney transplant allows a person whose own kidneys have failed to receive a new kidney from another person. A successful kidney transplant can improve many of the complications of kidney failure. A kidney may come from a living donor

or from an individual who died (a deceased donor). A living donor may be someone in your family, a friend, and in some cases may even be a stranger who wishes to donate a kidney to someone in need of a transplant.

HOW DO I START THE PROCESS OF GETTING A KIDNEY TRANSPLANT?

You can find a transplant center (a hospital that performs transplant operations) by state or region using the website of the Organ Procurement and Transplantation Network (http://optn.transplant.hrsa. gov/members/search.asp). You may also ask your healthcare provider about the transplant process. He or she can refer you to a transplant center for evaluation.

WHAT DOES THE TRANSPLANT OPERATION INVOLVE?

The kidney transplant operation involves surgery that opens the lower part of your abdomen to place the new kidney just above the front of your hip bone. The blood vessels of the new kidney are connected to your existing blood vessels, and the ureter (urine tube) is connected to your bladder. The operation usually takes about three to five hours.

WHAT ARE THE CHANCES THAT A TRANSPLANTED KIDNEY WILL CONTINUE TO FUNCTION NORMALLY?

A number of factors affect the success of kidney transplants. Generally, the chances that a transplanted kidney will continue to work correctly are between 89 – 95% one year after the

operation. Success rates of transplants are improving steadily as research continues.

WILL I NEED TO FOLLOW A SPECIAL DIET?

One advantage of a successful kidney transplant is that there are few dietary restrictions. If you were on dialysis before, you may now be able to eat more of the foods you had to restrict. Generally, transplant recipients are advised to eat a heart-healthy diet (low fat, low salt) and drink plenty of fluids.

HOW CAN I FIND OUT MORE?

iHablamos Español!



NKF*Cares*

(855.653.2273) nkfcares@kidney.org

Try to learn as much as you can by reading and talking to your healthcare team, as well as kidney transplant recipients. Call or email us for free brochures and additional information.

TRANSPLANT ELIGIBILITY: **ARE YOU ON THE LIST?**

By Risa Simon, NKF Peer Mentor and Founder of the Proactive Path Institute

No one would dispute the fact that dialysis is an essential, life-saving treatment for kidney failure. It is indeed remarkable that a machine can successfully do the work of your kidneys. While this technology helps its users survive, there is another option that many kidney patients feel gives them an even better life: kidney transplant.

There are many patients on dialysis who are "transplant eligible," but who haven't been evaluated for a transplant. Some dialysis patients could be missing out on an opportunity to improve their quality of life by exploring transplant as an option. Could you be one of them? Have you talked with your healthcare provider and considered your options?

If you are considering transplant as a treatment option, it's important to know that the longer you are on dialysis, the more likely you are to lose out on transplant opportunities. Taking too much time to find out about transplant may hurt your chances of getting one. This is because of illnesses and increased medical problems associated with being on dialysis. In simple terms, the sooner you get a transplant, the greater the chances of success.

If you are not yet on the transplant list, but are interested in the possibility of receiving a kidney transplant, talk with your healthcare provider. If you are already on the transplant wait list, make sure you are in touch with your transplant coordinator regularly and that all your labs and medical evaluation tests are up to date.

WHAT ABOUT LIVING DONATION?

Unfortunately, the demand for kidneys exceeds the deceased organ donor supply, so even if you are already on the wait list for a deceased organ donor, it's important to also consider living donation. The first step is to talk to your family and friends and to get the word out about your search for a living kidney donor.

On average, transplants from living donors last longer than those from deceased donors. Many friends and family members would want to help, but may not realize that healthy people can lead a normal life with only one kidney. Educate those around you and see if anyone would be interested in getting tested.



THE TOP SIX QUESTIONS **TO ASK YOUR HEALTHCARE PROVIDER:**

- 1. Will a transplant offer me a better quality of life than dialysis? How?
- 2. What would disqualify me from being able to get a kidney transplant?
- 3. Do I appear to be a good transplant candidate and if not — why not? Is there a possibility I could become eligible for a transplant in the future?
- 4. Can I request an evaluation or get a second opinion?
- 5. Are there ways I could become ineligible for a transplant after I've been approved?
- kidney donation opportunities?

ASK MORE

QUESTIONS!

Who Gets the Kidney?

Changes for Allocating Kidneys from Deceased Donors



Are you considering being evaluated for a transplant, or already on the waiting list for a kidney? If so, you should be aware that the **Organ Procurement and Transplant Network (OPTN)** and the **United Network for Organ Sharing (UNOS)** have recently made changes to the way that kidneys from deceased donors are allocated (distributed) to those waiting for a transplant.

These changes mean that:

- Transplant candidates who are highly-sensitized, people with blood type B, and minorities will have an increased chance of receiving a transplant.
- The new policy "sets back the clock" for adults 18 years and older who are on the transplant waiting list to the day they started dialysis. So once someone is placed on the list, their time spent on dialysis counts towards how they are prioritized on the list.
- The new policy will match recipients and deceased donors according to the "life expectancy" of the kidney. Candidates who are expected to need a kidney for the longest amount of time will be matched with the kidneys expected to function the longest.

The National Kidney Foundation anticipates that this new kidney allocation policy will protect the gift of life. The policy will extend the length of time a transplanted kidney functions for a recipient, improve fairness in the waitlist and improve the ability for those with rare blood types and high sensitivity to receive a deceased donor transplant. For more detailed information about this policy and transplant, visit www.kidney.org/kidneyliving

My healthcare provider told me I have heart disease in addition to kidney disease. What does this mean and what can I do about it?

Cardiovascular or heart disease means having problems with your heart and the blood vessels throughout your body. Over time, the blood vessels that bring blood to the heart and brain can become blocked from a buildup of cells, fat, and cholesterol. This reduces blood flow to the heart and brain and can cause heart attacks and strokes.

Dialysis patients are much more likely than the general population to develop heart and blood vessel disease. This increased risk is related to having kidney disease and other health problems like diabetes and high blood pressure. For this reason, it's very important for dialysis patients to follow steps to protect their heart and blood vessel health and to prevent problems from developing or getting worse.

One of the best ways to combat heart disease is to follow a healthy lifestyle. This includes following a heart-healthy diet, exercising regularly, stopping smoking, and controlling blood pressure. Also, if you are diabetic, you need to control your blood sugar. A heart-healthy diet includes limiting sodium and eating more foods that are rich in heart-healthy omega-3 fatty acids such as coldwater fish like salmon and albacore tuna, and other foods like flaxseed and canola oil. Reduce foods that are high in saturated fats and cholesterol such as red meat, organ meats, whole milk, cheese, and fried foods. If you are on a protein or potassium modified diet, speak to your healthcare provider and dietitian before making any changes in your diet.

Limiting fluid and sodium is very important in decreasing weight gain from water, which puts a great strain on your heart. Additionally, if your cholesterol levels and blood fats are too high, you may need to follow a low-fat diet and exercise more. Some patients may also need to take pills (such as a statin) to help lower cholesterol.

Speak to your healthcare provider to learn more about your risk for heart disease and how to improve your heart health. Your healthcare team will work with you to develop a care plan that meets your individual needs.

Are there different kinds of heart and blood vessel disease?



Yes. Some of the most common ones are:

- Coronary artery disease The most common form of heart disease. It affects blood vessels of the heart and causes angina (chest pain) and heart attacks.
- Left ventricular hypertrophy The muscle on the left side of the heart becomes thicker and does not work as well.
- Heart failure The heart is not able to pump blood around the body as well as it should. Heart failure develops slowly over time. It can have a large impact on your ability to perform daily activities.
- Stroke Lack of blood flow to the brain. A stroke may be caused by a blood clot or bleeding in the brain from a broken blood vessel.

Learn more at www.kidney.org/kidneyliving, call toll-free 855.NKF.CARES (855.653.2273), or email nkfcares@kidney.org



By Portia V. Wadley, Hemodialysis Patient

I've been a dialysis patient since May 2004. From the beginning, I wanted to do well with my treatments and live a quality life, so I decided to educate myself about kidney disease. I read the National Kidney Foundation's brochures, blogs and e-newsletters, and read all the materials from my dialysis center. I read whatever I can get my hands on!

I decided to create a journal to document everything related to my health, including my kidney disease.

My Health Journal includes a date and a description of any medical event, including symptoms I experienced, doctor's appointments, and follow-up care, such as:

- Urgent care visits
- Emergency room admissions
- Hospitalizations
- Outpatient procedures such as a kidney biopsy, access placement, etc.
- Lab test results
- Dialysis treatment schedules and information
- Surgeries
- Appointments and testing related to my kidney transplant evaluation

My Health Journal also documents my insurance coverage, declaration of being disabled by the Social Security Administration for end stage kidney disease, and my vaccination history including hepatitis B, flu, and pneumonia shots.

Toward the end of my Health Journal, I included three sections:

- **1.** My Healthcare Team: names, titles, location information, and phone numbers
- **2.** Medications: name, type, dosage, and description
- **3.** Emergency Contacts: name, relationship, address, and telephone

Creating a Health Journal was one of the best things I did for myself as a dialysis patient. It is a great source of information that I have used again and again. When I applied for disability and whenever I am admitted to the hospital, I have to refer to this document for specific dates of tests, access surgeries, and when I started dialysis. When I was evaluated for a kidney, the information in my Health Journal also proved to be invaluable. I gave my primary doctor and my dialysis unit a copy to file with my records. I keep a copy of my Health Journal in my medical file at home, so that family members can know my medical history. A lot of people don't know their family history, so even if you're not on dialysis, a Health Journal is worth creating.

Start your own Health Journal today!

And share your experience and tips for creating one with other readers on our website at **www.kidney.org/kidneyliving.** Your responses could appear in our next issue of Kidney Living's Voices section.



By Susan Lupackino, MHS, RD, LDN

When your kidneys fail, they cannot clean the wastes and toxins that build up in your body from the foods you eat. Once your kidneys stop working, dialysis can help clean your blood. Healthy kidneys filter the blood 24 hours a day, 7 days a week. Since dialysis treatments cannot replace this same workload, wastes can build up in your blood between dialysis treatments and make you sick. This is why it is important to watch what you eat and drink.

Here are 5 foods to limit if you're on dialysis:

Foods with phosphate additives

Foods such as deli meats, baked goods and soda contain phosphate additives. Phosphates are often used as a preservative in processed foods to extend the shelf life. Make sure to read the nutrition label carefully and look for anything that has "phos" in the ingredient list. Sodium phosphate is one example of a phosphate additive.

Bananas

Bananas are very high in potassium. One banana has 422mg of potassium. However, patients on peritoneal dialysis may be able to have higher amounts of potassium.

Nuts and nut butters

These are not only high in phosphorus, but also are high in potassium. One ounce of cashews (about 18 cashews) has 187mg of potassium and 150mg of phosphorus. One tablespoon of peanut butter contains 119mg of potassium.

Chocolate

A 3.5 ounce serving of dark chocolate has over 300mg of phosphorus. Chocolate also contains about 150mg of potassium.

Salty Meats

Bacon, ham, sausage, hot dogs, lunch meats, canned meats, and bologna are very high in sodium.



Susan Lupackino is a nutritionist specializing in diabetes, dialysis, sports nutrition, and weight management.

Spice up your spring! Exotic Recipes



Chicken Pad Thai

Serves 8 (Serving size 1 cup)

INGREDIENTS:

1 pound low-sodium rice noodles ¹/₄ cup vegetable oil 3½ cup cooked chicken, sliced 1 tablespoon minced garlic 4 green onions, sliced diagonally 1 chili pepper, diced 1 egg ²/₃ cup Pad Thai Sauce (recipe below) 1 lime 1/8 cup cilantro, chopped **Pad Thai Sauce** 2 tablespoons vinegar 2 tablespoons lime juice 1 tablespoon fish sauce 1/2 cup sugar subsitute 1/2 cup water

DIRECTIONS:

 Soak rice noodles for approximately 40 minutes. Cook chicken, then slice.
 Mix ingredients for Pad Thai Sauce.
 Sautée garlic, pepper, and half of green onions in ¼ cup of oil.
 Add noodles. Toss to coat.
 Add egg; cook thoroughly.
 Add Pad Thai Sauce. Toss to coat.
 Add remainder of juice from one lime and top with chicken and cilantro.

ANALYSIS:

calories 382 protein 22g total fat 10g carbohydrates 49g sodium 254mg potassium 212mg phosphorus 243mg

Submitted by Denon Stacy, MS, RD, LD



Chicken and Sausage Jambalaya

Serves 10 (1 cup per serving)

INGREDIENTS:

2 cups white rice, cooked according to package directions (yield 6 cups cooked rice)
1 tablespoon butter
½ onion, diced
¼ bell pepper, diced
2 stalks celery, diced
2 cloves garlic, minced
2 chicken breasts
4 ounces turkey sausage
1 cup low sodium chicken stock
½ cup low sodium tomato sauce
½ tsp pepper
¼ tsp cayenne pepper

DIRECTIONS:

 Cook chicken through until 165°F. Let cool. Shred.
 Meanwhile, cook rice according to package directions.

 Add butter to a separate pan.
 Then add bell pepper, onion, celery, and sausage. Cook until vegetables soften, onions are translucent, and sausage is browned (about 3-5 minutes).

5. Combine rice, chicken, vegetables, stock, spices, and tomato sauce. Simmer until reduced.

ANALYSIS: calories 191 protein 9.5g total fat 4.9g carbohydrates 24g sodium 119mg potassium 105mg phosphorus 67mg

Submitted by Denon Stacy, MS, RD, LD



Bunless Quinoa Lamb Burgers

Serves 8 (2 ounces meat per person)

INGREDIENTS:

1 cup whole-grain, uncooked quinoa 1 pound raw ground lamb raw (or turkey) 1 egg, whisked 4 garlic cloves, minced 1 tablespoon fresh, grated ginger (or minced) ½ teaspoon cumin

- 1/2 teaspoon ground black pepper
- 1/4 teaspoon smoked paprika
- 2 tablespoons fresh mint, chopped
- 1 tablespoon fresh cilantro, chopped
- 1 tablespoon fresh chives, chopped
- 2 tablespoons sesame oil
- 1/2 red onion, thinly sliced
- ¹/₂ cup Tomato-Free Curry Ketchup (see recipe at right)
- 2 teaspoons salt-free curry powder 8 tablespoons crème fraiche or 0% Greek yogurt
- Green cabbage or butter lettuce

ANALYSIS:

calories 210 protein 15g total fat 10g carbohydrates 15g sodium 58mg potassium 317mg phosphorus 199mg

DIRECTIONS:

1. Cook quinoa according to package directions.

 Pour cooked quinoa into a large mixing bowl and set aside to cool, 10 minutes

3. Add the raw lamb, egg, garlic, ginger, black pepper, paprika, mint, cilantro, and chives to the quinoa bowl.
4. Using your hands, mix all the ingredients together until combined.
5. Form 8 burger patties and set aside on a plate.

6. Heat a tablespoon of sesame oil in a large skillet and when hot, add 4 patties to pan. Cook 8 –10 minutes per side.
7. Place done burgers on a clean plate and cover with foil. Repeat with the remaining patties and set aside.
8. Add onion slices to pan with leftover meat juices, and cook until the onions have softened and caramelized, about 5 to 8 minutes.

9. While onions cook, mix Tomato-Free Curry ketchup with the curry powder in a separate bowl.

10. To plate, put a single burger in a cabbage leaf. Then layer the toppings as follows: 1 tablespoon crème fraiche or Greek yogurt; 1 tablespoon Tomato-Free ketchup; and about 1 tablespoon of the sautéed onions.

Curry Ketchup

Serves 8 (Makes 2 cups)

INGREDIENTS:

3 red bell peppers, stems & seeds removed ¼ cup apple cider vinegar

- ½ cup dark brown sugar
- 1 teaspoon freshly ground black pepper
- ½ teaspoon balsamic vinegar
- ¼ teaspoon no-salt garlic powder
- ¼ teaspoon smoked paprika

DIRECTIONS:

1. Chop the bell peppers into large chunks and place them in a food processor or blender.

2. Add the apple cider vinegar and blend until smooth.

 Pour mixture into a small pot or saucepan, add the brown sugar, balsamic vinegar, black pepper, garlic powder, and smoked paprika and bring to a rolling simmer over medium heat.
 Cover and cook over low heat until mixture is reduced by a third, about 15 minutes.

5. Keep the ketchup warm on low heat with the pot or saucepan covered.

- (To save for later use, place in an
- airtight container and refrigerate.
- Ketchup will keep for 1 week).

Relaxation & EUN

What do you do to take a break and relax? What hobbies help you feel good and have fun?

I have so many hobbies and interests that I don't know where to start! I swim about 4 days a week and I've just started taking zumba classes. I thoroughly enjoy being a pen pal to people around the world, blogging, and writing poems. I adore cooking. Most of all, I love spending time with my friends and family. Enjoy life, and never be afraid to try something new that you may end up loving! – Mary W.

I love to get out and enjoy God's creation: the birds' songs, and the beautiful clouds and colors, the breeze that refreshes me. I love playing brain games to try and keep myself sharp.

- Harriet
- Go fishing.
- Michael Wayne R.

Taking a break and relaxing for me means going to the movies (mysteries and crime stories are my favorites). My hobbies are reading romance novels and playing "FreeCell" for hours at a time. – Jacqueline M.

I enjoy going to concerts, movies, art museums, reading, and spending time with my friends. I hope to do more traveling in the future. – **Michaela A.**

Cooking, spending time with grandchildren, and great grandchildren. I also have a great, great grandson, and I love being with him!

– Patsy B.

I love to quilt and also enjoy reading, knitting, and crocheting. We try to get some exercise as often as time allows. – **Diana G.** I relax by making latch hook rugs, wood burning, and building model cars, and I am trying to learn to do wood carving.

- Donald S.

I have a comfy chair by my back window and have a bunch of bird feeders in the back yard. I sit with my bird books and see just how many different birds there are and check for a new one. Or sometimes I just sit and drink a glass of tea and watch the birds. Sometimes I get a surprise when deer or a raccoon shows up. Very relaxing and very enjoyable. – Cecilia J.

My wife and I have a side-by-side bike. We ride close to our home, we do some woodworking, and we also like to walk through antique malls. - Jimmie G.



I am 87 years old and I love watercolor painting. I teach art one day each week and take art classes myself too. I also love going to the movies.

– Rudi S.

I walk alone or with my Boston terrier. I also just started taking a "gentle yoga" class once a week. About 3 times a year I have a wonderful massage.

- Sara

I do genealogical research on my family as well as the families of those marrying into my family.

- Robert G.

I keep myself busy with volunteer activities, making quilts, and taking a class once a week. I plan trips away from home and enjoy the time spent. I will not allow dialysis to change my life!

- Peggy S.

I was fortunate enough to grow up with a mother who knew her way around the kitchen. She taught me everything she knew. Regardless of what emotion I'm feeling, whether it's a celebration or stress, my "go to" when I need a break and to get away is to be in the kitchen. Cooking, especially baking, helps me to escape to where I'm in control of the outcome. I get to create something wonderful and delicious out of nothing and to me that is special. It relaxes me in a way nothing else can. Most people think cooking is a chore, but for me it's fun and allows my brain to stop focusing on everything else for a while, and just concentrate on doing something I love. There is no better escape than that.

– Alexandra H.



I play Club Pogo, read, and spend time with my grandkids. I also work at the dialysis center where I receive my treatments, having just passed my nursing exam in July of 2013. That gives me peace of mind to know I am still contributing while managing my kidney disease.

- Kathryn C.

Photography. Playing unusual table games with my family. Watching the birds at the feeder on our rear picture window.

- David M.

I make sure I make time to do fun things with my family and friends. Going out for dinner or getting together to play cards, all help me to relax and laugh!

- Martha S.

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