



National  
Kidney  
Foundation®

# kidney living®

Summer 2015

Issue 11

**BARBECUE**  
IT'S HOT!

**ADVOCACY**  
KIDNEY PATIENTS  
TAKE ACTION

**7 TIPS**  
FOR DATING  
ON DIALYSIS



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# kidney living®

A MAGAZINE FOR PEOPLE ON DIALYSIS

## A Note from Kevin

As someone who has a long history with kidney disease, I am excited to be the new interim CEO for the National Kidney Foundation (NKF). Kidney disease has been a part of my life for as long as I can remember. My maternal grandfather died of kidney failure in 1953. He was only 41 years old. My mother has been living with kidney disease most of her adult life and has been on dialysis for the past 4 years.

When I was 40 years old, I was diagnosed with FSGS. I know first-hand how early detection and preventative actions can slow or prevent the progression of kidney disease. I was on peritoneal dialysis and then I was fortunate to receive a kidney transplant from a deceased donor in 2004.

The NKF has always been a leader in the kidney community. One of our major priorities is advocating for kidney care, urging legislators to elevate kidney disease to the congressional forefront. It is imperative that we increase research funding, improve treatment for patients, and protect living donors. As a kidney recipient, the gift of life from an unknown donor is a daily reminder of the importance of increasing the donor pool and decreasing the number of people on dialysis.



To learn more about NKF's new initiatives and ways to get involved visit [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving).

Kevin Longino

A handwritten signature in black ink, appearing to read 'Kevin Longino'.

Interim CEO, National Kidney Foundation  
Kidney Transplant Recipient

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## What's in this Issue?



### FEATURE ARTICLE

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From Diagnosis to Dream Come True

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How has kidney disease or dialysis affected your personal relationships or dating life? Do you have any advice to share?

An illustration of a male doctor with brown hair and glasses, wearing a white lab coat over a yellow shirt and an orange tie. He is holding a grey clipboard in his left hand and pointing his right index finger upwards. Above him is a large, light blue heart shape. Inside this heart, there is a smaller red heart and a grey heart that overlaps it. The background of the illustration is a light blue circle.

# WHAT'S *Love* GOT TO DO WITH IT?

**Even without health problems, dating's never easy. In many situations, having to talk about a health or personal issue can be challenging or cause anxiety.**

If you have kidney disease it is a part of your life, but it doesn't define who you are. For this reason, your diagnosis isn't something that you necessarily need to share right away. Many people have things they are nervous about discussing when dating, whether it is a chronic disease or a life circumstance, such as being divorced, having children from another relationship, or even a recent break-up.

**Kidney disease doesn't have to adversely affect your love life.  
Here are tips for dating and communicating with a romantic partner.**

**♥ Open communication is key.**

Many people don't know what kidney disease and dialysis entail. They may have some misconceptions that might cause fear. Allow them to ask you questions, and make it an open door discussion. You don't need to discuss all the details right away, but you can build on knowledge and understanding as the relationship progresses.

**♥ Timing is everything.**

Don't feel obligated to immediately reveal that you have kidney disease. Get to know the person and tell them when the time feels right.

**♥ Be patient.**

Change can be scary, so be patient with your partner as he or she processes what this diagnosis means for him or her, for you individually, and for you both as a couple. Be honest about your feelings and encourage your significant other to share theirs. We often try to protect those we love and care about from difficult feelings; however, this can leave you feeling isolated.

**♥ Put your best foot forward.**

Think about how you view yourself and remember to lead with your best characteristics. Do you see yourself as independent? Strong? Sick? It's okay to view yourself in many ways, but start by highlighting your best qualities, just like you would on a job interview.

**♥ Be open about the sexual side effects.**

Sexual problems can happen to anyone, regardless of whether they have kidney failure. Admittedly, these are never easy to talk about, especially in a new relationship, but it's important that you be open with your partner. Also, talk with your healthcare team about any problems you are experiencing, because there may be treatment available.

**♥ Be in tune with your energy level.**

Keep your dialysis schedule in mind and make note of when you typically have the most energy. Try to plan your dates around these times when you're feeling your best, and don't overdo it with activities that will wear you out. For example, if you're feeling tired, suggest seeing a movie together instead of going for a long walk or hike.

**♥ Check out restaurant menus ahead of time.**

This way, you'll be able to find items that will work with your dialysis diet. By planning ahead, you can make other meal adjustments during the day, such as reserving some of your fluid intake or nutrient allowances for your date.

**communication is key**



Most romantic partners, like friends and family, will want to support you, but they might not always know how best to do that. Everyone has had struggles in their life. Sharing hard times or experiences can bring couples closer and increase intimacy. Learn more about talking with loved ones at [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving)

from diagnosis to

# Dream come true

Felicia Curry was shocked when shortness of breath led to a week-long hospitalization in 2011. She had been diagnosed with high blood pressure 10 years earlier, but had never thought her condition was that serious, and was inconsistent in taking her prescribed medications. As time passed, her high blood pressure took its toll, eventually destroying Felicia's kidneys and landing her in the hospital.

The medical team told her that she would need to go on dialysis. While a tough diagnosis to swallow, Felicia says, "I took it in stride because I know that I played a role in it. By not taking my high blood pressure medications regularly, I contributed to my kidney failure, and in order to survive I needed to accept responsibility and seek treatment."

Felicia's positive attitude and resolve to live in the moment, instead of dwelling on the "should've, would've, could've," has made her a positive role model for other patients at the dialysis unit.

One day at her dialysis center, she noticed an unfamiliar man receiving treatment on the other side of the room. "I had never seen him before," says Felicia, "but he immediately

caught my eye." She was determined to talk with him and learn more about this new, attractive gentleman.

Felicia's first order of business was to find out whether he was romantically available. After she discovered that he was single, Felicia sauntered over to her romantic prospect and introduced herself.

As the saying goes, the rest is history. Felicia and Reginald have been inseparable ever since. They were married this past January, a year to the date of their first fateful meeting.

Felicia attributes their compatibility and chemistry to not only their personalities, but to their mutual

understanding of what it's like to want to thrive and lead a normal life while managing a chronic health condition.

"We have a true partnership that isn't based on traditional gender roles," Felicia says, "For example, if one of us is tired or not in the mood to cook or clean, the other will pitch in. I'm a big believer in the idea that there's someone for everyone, and for me, Reggie is my soul mate. We support one another in a way that neither of us needs to pretend to be something that we're not."





# MORE EXPECTANT MOTHERS on dialysis

According to new findings presented at the National Kidney Foundation's 2015 Spring Clinical Meetings, pregnancy in women with kidney failure is becoming more common as the number of people with kidney disease in the U.S. increases.

Although severe kidney disease can make it hard to become pregnant, a survey by Drs. Mala Sachdeva, Jyotsana Thakkar, and Ilene Miller of the Hofstra North Shore - LIJ School of Medicine reported that 43% of the 75 U.S.-based nephrologists they surveyed had cared for pregnant women on dialysis.

"Before this survey, it had been more than 15 years since data had been collected on pregnancy outcomes for women on hemodialysis in the United States," said Dr. Sachdeva. "We wanted to provide an update by evaluating the current U.S. experience, including overall practice patterns and certain maternal and fetal outcomes that have occurred with this specific patient population."

According to the survey, pregnant women receiving hemodialysis treatment ranged from those who initiated dialysis during pregnancy

(32%), those who became pregnant during the first five years of treatment (58%), and those who became pregnant after being on dialysis for 5 or more years (10%).

Most nephrologists prescribed dialysis 4 – 4½ hours a day for six days per week. The survey revealed no maternal deaths, but 23% of pregnancies did not result in live births, and 50% were complicated by preeclampsia, a condition marked by high blood pressure and the possibility of poorer maternal and fetal outcomes.

For dialysis patients, some changes in your body make it hard to become pregnant. For example, most women on dialysis have anemia (a low red blood cell count) and also experience hormone changes. This may keep you from having regular menstrual periods. If you are thinking of becoming pregnant, talk to your healthcare

provider. If you become pregnant, you will need close medical supervision, changes in medicine, and more dialysis in order to have a healthy baby.

"With the increasing prevalence of kidney disease, there are now more women of child-bearing age living with kidney failure," said Dr. Kerry Willis, Chief Scientific Officer at the National Kidney Foundation. "This survey highlights that the impact of dialysis practice on maternal and fetal outcomes requires further study."

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*If you are thinking  
of becoming  
pregnant, talk to  
your healthcare  
provider.*

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To learn more about pregnancy and kidney disease, visit: [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving)



2ND  
ANNUAL

# KIDNEY PATIENT SUMMIT

Hosted by the NKF in Washington, D.C.

This powerful event kicks off National Kidney Month in March. It allows individuals affected by kidney disease to speak directly to legislators and urge them to make kidney care a congressional priority. Attendees met with Members of Congress and their staff to share personal stories and advocate for policies that will raise awareness of kidney disease, increase research funding, improve treatment for patients, and protect living organ donors.

“My kidney disease is genetic, but for so many Americans it can be prevented. Collectively, we can all get something done to change the course of kidney disease.”

—Jummy Olabanji

Jummy Olabanji, an anchor at ABC7 in D.C., was the master of ceremonies. She found out she had a genetic kidney disease after going to the doctor for high blood pressure. She’s also doing something about it — she changed her diet and has started running to keep her kidney disease in check.

Curtis Cotton, of New York, also participated in the Kidney Patient Summit. Curtis has been on in-center dialysis since his kidneys failed due to high blood pressure in 2001. The Summit exposed Curtis to a world of new ideas and people. He met other dialysis patients, living kidney donors, and countless others who had different causes of kidney disease.

"It's been good to see some of the other faces of kidney disease," he said. "Kidney patients need to be more active and find out what's going on in the kidney community and how they can help. There's no excuse for not getting involved!"

What can you do? Join our Advocacy Action Center at [www.kidney.org/takeaction](http://www.kidney.org/takeaction) and ask your representatives to:

1. Improve early detection, diagnosis, and management of kidney disease in Federal Health programs.
2. Ask for an increase in funding for the National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK). Contact your representative on the House and Senate Appropriations Committees and ensure funding for kidney disease research at the NIDDK is increased by 6% over the President's proposed budget.
3. Strengthen the Medicare ESRD program for kidney patients! Ask your representative to:
  - a) Support the Chronic Kidney Disease Improvement in Research and Treatment Act (S. 538/HR 1130) to allow dialysis patients the choice to enroll in Medicare Advantage, which has caps on the amount



Haley Newkirk, kidney recipient from Colorado, speaks to her representative

people can be required to pay out of pocket for medical care.

b) Extend Medicare coverage of immunosuppressive drugs for the life of the kidney transplant. Currently, Medicare coverage ends 36 months post-transplant for those under age 65.

4. Help protect living donors by asking your representative to cosponsor the Living Donor Protection Act. This bill will prohibit insurance companies from discriminating against living donors and will extend employment protection to living donors under the Family Medical Leave Act.

Join our Advocacy Action Center to take action on all these issues — it's quick and easy!

[www.kidney.org/takeaction](http://www.kidney.org/takeaction)





## DIET MISTAKES

by Linda Ulerich, RD

**you don't  
want to make**

When you have kidney failure, there are dietary restrictions that have to be followed in order to keep your body from building up dangerous levels of certain toxins that healthy kidneys are normally able to remove. You may need to limit potassium, sodium, and phosphorus. Sometimes it is difficult to sort through the details of each restriction and know where to focus your efforts.

Here are some misconceptions about the dialysis diet. If you are on peritoneal dialysis, you may have a more liberal diet, because peritoneal dialysis is done more frequently throughout the day.

### **"I can tell if something is salty by how it tastes."**

Although you might be fairly good at identifying salty foods by their taste, you will not be able to tell how much sodium is in that food if you don't read the label. If you are allowed 2,000 mg of sodium a day, you can work in a food that has higher sodium content, but only if you read the labels and make sure you stay within your daily sodium allowance.

### **"If I don't eat a lot of sodium today, I can have more sodium tomorrow."**

Don't save up the sodium allowance from one day to the next. Your body may not be able to handle the extra sodium, and this could result in too much fluid weight gain. You may not be able to correct this easily with medications or your usual dialysis session.

### **"Low potassium foods are safer and I can eat as many of them as I want."**

Foods low in potassium can end up being high in potassium if you eat enough of them. Blueberries are a low potassium fruit, but if you eat several servings in one day, this may be more potassium than your body can handle, especially if you are still eating usual amounts of other foods.

### **"I can eat extra high potassium foods the night before my next dialysis session because it can be dialyzed off the next day."**

Consuming too much potassium the day before dialysis can lead to higher levels than your body can tolerate. High levels of potassium in the blood cause the heart to beat irregularly and can even make the heart stop. It is best not to take chances when it comes to high potassium foods.

### **"I can eat out as long as I pay attention to the sodium and potassium content of the foods I am eating."**

Don't forget about phosphorus! Phosphorus from the foods you eat builds up quickly in your body. Many foods served at fast food restaurants contain high amounts of phosphorus that may not be listed on the nutritional information they provide. You can take more phosphorus binders to help bind up the extra phosphorus, you first need to know where the phosphorus is in those fast food items.

**Talk with  
your dietitian**  
about your specific  
needs so they  
can assist with  
safe food choices!



# HELP!

## My medications are so expensive!

I know I need to take them, but I'm struggling to pay each month.  
My family could really use the money elsewhere. Is there any help out there?

Medications can be very costly; however, there are programs that can help. If you are having trouble paying for your medications, the first step is to talk with your dialysis care team. Each patient has different insurance coverage and a particular medication that is expensive on one person's plan may not be as expensive on another.

Typically, Medicare Part D pays for medications for most patients unless you have private insurance. There are many Medicare Part D plans. Each plan places medications on "tiers" and the amount you pay (co-pay, deductible) may be different depending on which tier your insurance company places a particular medication. Talk with your doctor, advanced practitioner, and/or pharmacist to see if there are lower cost options available. Brand name drugs are often more expensive than generic versions.



If you have Medicare and you are having trouble paying for your prescriptions, it is important to apply for "Extra Help" with your prescription drug plan costs. The Extra Help is estimated to be worth about \$4,000 per year. Eligibility is based on income; however, it's always worth applying to see if you might be eligible for assistance. To learn more, visit [www.ssa.gov/medicare/prescriptionhelp/](http://www.ssa.gov/medicare/prescriptionhelp/).

Additionally, some of the companies that make medications offer assistance. The NKF has compiled a list of financial assistance programs for common dialysis medications. These programs are based on income, so check with your social worker or the manufacturer for the eligibility. Often, the application for financial assistance has to be submitted by your social worker.

Find help at [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving) or by contacting NKF Cares toll-free **855.653.2273** or [nkfcare@kidney.org](mailto:nkfcare@kidney.org).



## Spicy Barbecue Sauce

Serving size: 1 tablespoon, Add to your choice of chicken or pork!

### INGREDIENTS:

¼ cup dark corn syrup  
 ¼ cup red wine vinegar  
 ¼ cup onion, chopped  
 1 cup water  
 2 tsp dry mustard  
 2 tbsp tomato paste  
 1 tsp Tabasco® pepper sauce  
 1 tsp Mrs. Dash®  
 (variety of your choice)  
 2 tbsp vegetable oil  
 1 tsp all-purpose flour

### DIRECTIONS:

1. Mix all ingredients together except vegetable oil and flour in a sauce pan.
2. Mix vegetable oil and flour together in separate container to make paste.
3. Add to sauce pan, cook on low heat until desired thickness is reached.
4. Pour or brush on baked or grilled meats.

Yield 1½ cup (24 servings)

**ANALYSIS** Calories 28, Protein 0 g, Total Fat 1 g, Cholesterol 2 g, Carbohydrates 2 g, Sodium 28 mg, Potassium 34 mg, Phosphorous 1 mg

## Fresh Fruit

Serving size: ½ cup

For a fresh, healthy end to your BBQ meal, try simple fresh fruit for dessert. You can make a fruit salad by mixing them or eat them alone! Here are some kidney-friendly favorites:

Raspberries  
 Blackberries  
 Strawberries  
 Pineapple  
 Apples  
 Grapes



## NKF Pasta Salad

Serves 4

### INGREDIENTS:

2 cups dry fusilli pasta  
1 cup grated carrots  
1 cup sweet yellow corn (raw)  
1 cup green peas (raw)  
½ tbsp chopped basil–fresh  
¼ tsp ground black pepper  
2 cups ½" pieces green beans–fresh  
½ cup chopped spring onions  
or scallions  
½ cup olive oil, plus 1 tbsp  
½ cup lemon juice–fresh  
2 tsp dry mustard  
1 tbsp parsley–fresh



### DIRECTIONS:

1) Cook pasta in boiling water until al dente. Drain and let cool. Toss pasta with 1 tablespoon of olive oil in a bowl. Set aside. 2) Blanch green beans by dropping into boiling water for 2 minutes. 3) Transfer beans to a colander and chill under cold running water. Drain. 4) In a large bowl combine the beans, corn, grated carrots, peas, lemon juice, 1/3 cup olive oil, mustard, parsley, and basil. 5) Add green onions, pasta and pepper. 6) Toss, cover, and chill for at least 1 to 2 hours.

**ANALYSIS** Calories 297, Protein 6.8 g, Total Fat 15.4 g, Cholesterol 0 mg, Carbohydrates 36 g, Sodium 22 mg, Potassium 303 mg, Phosphorus 72 mg



## Baked Summer Squash Serves 6

### INGREDIENTS:

2 tbsp margarine or butter, melted  
¾ tsp thyme  
½ tsp black pepper  
1 yellow squash, sliced  
1 zucchini squash, sliced  
1 medium onion, chopped  
1 small stalk celery, chopped  
1 large bell pepper, chopped  
1 tbsp lemon juice

### DIRECTIONS:

1. Preheat oven to 350°F.
2. Sauté all ingredients (except lemon juice) in margarine. Cook until onions are translucent.
3. Add lemon juice.
4. Place sautéed mixture in a casserole dish.
5. Bake approx. 30 minutes. Serve hot.

**ANALYSIS** Calories 49, Protein 1 g, Total Fat 3 g, Carbohydrates 5 g, Sodium 34 mg, Potassium 139 mg, Phosphorus 25 mg

Recipes courtesy of the Georgia Kidney Cookbook. For more, visit [www.kidney.org/kidneyliving](http://www.kidney.org/kidneyliving)

# What's it all About?

# Palliative Care

Too few patients, family, and caregivers are aware that palliative care can, and should be, offered to all people living with serious illnesses, including kidney failure. Palliative care could be right for you.

## WHAT IS PALLIATIVE CARE?

Palliative care is a specialized area of medical care that can help maintain comfort as well as relieve pain, other symptoms, and stress of illness. Board-certified palliative care specialists partner with you, your family, your nephrologist, and other healthcare professionals to provide comprehensive medical care focusing on reducing pain, maintaining comfort, and managing symptoms. Palliative care is *not* hospice; however, hospice patients can benefit from palliative care.

The goal of palliative care is to improve quality of life for both the patient and the family. "Palliative care can alleviate the toll that life with a serious illness can take on families," said Diane E. Meier, MD, director of the Center to Advance Palliative Care (CAPC), a national organization dedicated to increasing access to quality palliative care services. "Palliative care puts control back in the hands of the patient and family, and it can extend patients' lives."

## HOW CAN PALLIATIVE CARE HELP DIALYSIS PATIENTS?

- Manage pain and other conditions related to kidney disease.
- Palliative care is provided alongside dialysis treatment and helps provide relief from conditions related to kidney disease, including high blood pressure, heart disease, and diabetes.
- Help in communicating with your other doctors and evaluating treatment options.
- Palliative care is a team approach to care and will work side-by-side with your nephrologist and/or transplant team to support you. They can help you make critical decisions about treatment options such as deciding whether or not to start dialysis. If you are already being treated with dialysis and your health is declining, palliative care specialists can help you transition to managing your disease without it.
- Explain what to expect throughout the illness.
- Your palliative care team will spend as much time as you need to help you and your family members better understand your conditions, available treatment options, and overall effects of treatments on your health.
- Help you cope with worry, stress, or depression.
- The burden of kidney failure can be heavy — in addition to related symptoms and difficult decisions regarding your care, you may have emotional, spiritual, and practical concerns. Palliative care provides emotional support for both patients and their families. Your palliative care team can often provide additional therapies, including massages, talk therapy, and relaxation techniques, to ease emotional and spiritual stress.

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For more information on palliative care, please visit [kidney.org/kidneyliving](https://www.kidney.org/kidneyliving).

## How has **KIDNEY DISEASE** or **DIALYSIS** affected your romantic relationships?

# Relationships, Dating, and Dialysis

Kidney disease has had a profound impact on my relationships. Now as for dating, I can't say that I have that worked out. I still want a life partner, and maybe to be married some day. I hope that some day I can once again find love, but until that time, I will give love to those who come through my life, and aspire to being a whole human being. *Shar C.*

When I was first diagnosed with kidney failure, I thought it would be hard to be with someone accepting me and my health issues. Currently, I have been in a successful relationship with unbelievable passion, since February 2015.... love is always possible. *Darlean R.*

I got a transplant last April while I was dating someone. He said it was too much for him, so I am no longer dating him, but am now dating someone else. It is very important for me to always tell the truth about how I feel, to be kind and compassionate to myself and everyone else. *July R.*

When I fell ill I kept my illness private — only sharing details when I absolutely had to. As I started telling people, the calls, cards, messages, and prayers started coming in. As my health continued to deteriorate, those calls, cards, and messages provided me so much comfort. My health has improved dramatically — no doubt in part due to the comfort I received from those caring messages. Don't be afraid to let people in. *Bob M.*

I am sorry, I have no sound advice for relationships or dating. I don't have a significant other. I do think that there should be no real problem for someone to have a relationship. As long as the person you are with knows your situation and cares enough for you there should, in my opinion, be no problem. I have seen many an odd couple in my day and I don't see where a bad kidney could get in the way of love or a friendship. *Clorinda B.*

Dialysis caused me to plan dates and other events around treatment days. I try not to plan dates after dialysis in case of fatigue which may or may not be present. *Wanda W.*

For more **Kidney Living Voices** and to share your thoughts, please visit [kidney.org/kidneyliving](https://www.kidney.org/kidneyliving)



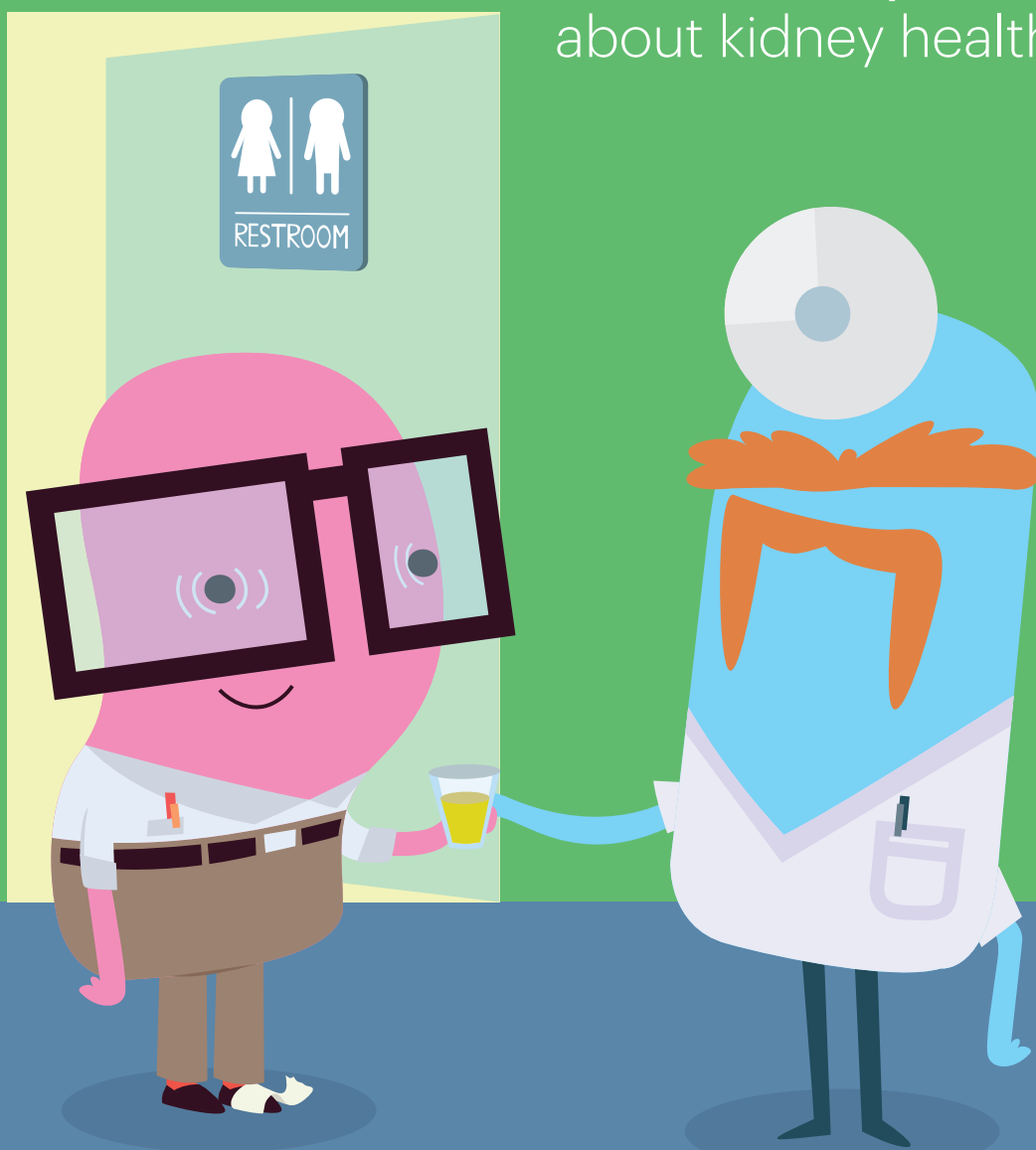
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