



National
Kidney
Foundation™

kidney living

Winter 2014

Issue 5

WARM UP YOUR WINTER!

FAST, HEARTY MEALS
FROM THE KIDNEY
KITCHEN

PERITONEAL DIALYSIS

ONE MOM LIVES LIFE
TO THE FULLEST

LET'S WALK!

THE NATION IS WALKING
TO END KIDNEY DISEASE



PATIENT EDITORS

Meg Banks
Poughkeepsie, NY

Dorothy Davis
Birmingham, AL

Sheldon Francis
Bronx, NY

Celeste Castillo Lee
Ann Arbor, MI

PROFESSIONAL EDITORS

Dawn Berry, RD
West Des Moines, IA

Eileen Boyte, MSW
Los Angeles, CA

Mark Conard, PhD
Darien, IL

Denise Eilers, BSN, RN
Davenport, IA

Maria B. del Rosario, MD
Worcester, MA

Dodie M. Stein, PhD, MSW, LCSW
Indianapolis, IN

Mandy Trolinger, MS, RD, PA-C
Highlands Ranch, CO

Roberta Wager, RN, MSN
San Antonio, TX

IN-HOUSE STAFF

Jennifer Martin
Executive Editor

Kelli Collins, LICSW
Editorial Director

Bernard Rittersporn
Managing Editor

Staci McKeown
Design Director

kidney living

Happy New Year!

When I first started dialysis, I was 62 years old. My family was grown and I was teaching full time. Retirement was looming, but I wasn't there yet. After studying my treatment options and consulting my nursing staff, it became obvious that peritoneal dialysis (PD) was the right choice for me. PD seemed to be the least restrictive to my lifestyle. It would enable me to do my treatment while I slept and be ready to get up and go to school in the morning. I felt more rested and healthier than I had in a long time.

For me, PD offered a lifestyle without interruption. Travel arrangements were easy to make with the help of my clinic, whether I was planning for an overnight stay or traveling for an extended period of time. Although life has changed, there really isn't anything that I can't do now that I could do before.

Almost four years after starting dialysis, I've finally retired and PD is working as effectively as ever. While I wait for a new kidney, PD keeps me going strong. This New Year, I plan to continue enjoying time with friends and family, and I'm also looking forward to taking our annual trip to Las Vegas! No matter what type of dialysis you choose, I hope you all find ways to stay healthy, happy, and motivated to improve your health this coming year too!



Meg Banks

Meg Banks
Patient Editor, Kidney Living

National Kidney Foundation

30 East 33rd Street
New York, NY 10016
800.622.9010 | 212.889.2210
Email: kidneyliving@kidney.org
www.kidney.org/kidneyliving

kidney living is published by the National Kidney Foundation (NKF). Opinions expressed do not necessarily represent the position of the NKF or its sponsor. The NKF reserves the right to edit all articles. Please contact the NKF for article submission guidelines or permission to reprint articles.

© 2013 National Kidney Foundation, Inc. All rights reserved. 01-65-6208_KBD



What's in this Issue?

FEATURE ARTICLE

4

Peritoneal Dialysis and a Positive Mindset

Candria Denzmore talks about PD and living life to the fullest.



IN EVERY ISSUE....

11

Kidney Kitchen

Dining Out Tips plus Hearty Dishes to Warm up your Winter

14

Ask Your Healthcare Team

What should I tell my family and friends about my kidney disease?

15

kidney living Voices

What are your New Year's resolutions for staying healthy while living on dialysis?



AFFORDABLE CARE ACT:
What You Need to Know...6



Candria Denzmore, a wife and mother of three teenage boys, first came to know kidney disease through the caregiver role: when her husband, Nathan Rice, was diagnosed with kidney failure.

Candria and her family researched treatment options and decided that peritoneal dialysis (PD) would be the best fit for Nathan and later, when she was diagnosed with kidney failure, for her.

"Peritoneal dialysis allows me to dialyze daily. I feel much better knowing that my blood is being cleaned each night while I sleep," said Candria. "I'm home the whole time and awake with plenty of time to get my kids up in the morning to get them ready for school." She continues, "It was really important to me that I didn't have to worry about disrupting my kids' schedules or missing their activities because I needed to dialyze."

Candria insists on living life to the fullest and not letting kidney failure stand in the way of her parenting, her positive attitude, or her travels. She recently returned from a trip to Las Vegas and has even taken cruises while on dialysis. "I usually travel about three times a year. It requires some planning

to ensure that all of my supplies are shipped directly to the hotel or boat, but there is no change to my overall routine."

While her experience with PD has been quite positive, Candria has also faced some challenges. "I've gained about 40 pounds and it has been difficult to lose the weight. Because my blood is cleaned inside my body, a cleansing solution called dialysate flows into my abdomen through a catheter. This solution is high in sugar, and can cause weight gain for some people, including me."

Candria says that keeping a positive attitude helps and so does helping other patients as a mentor with the NKF Peers program. "Life doesn't stop because dialysis starts. I always tell people to continue to do the things they love and enjoy — whether that is traveling, simply taking a walk, or going to the movies with friends or family. Create your own normalcy. Don't let dialysis define you or prevent you from being happy."

For more information about the NKF Peers program and peritoneal dialysis, please visit:
WWW.KIDNEY.ORG/KIDNEYLIVING

YOU'RE THE EXPERT

By Maria B. del Rosario, MD

When a person says they are on dialysis, it is often assumed that he or she is on **hemodialysis**. More than 90% of dialysis patients receive in-center hemodialysis and therefore many people, including healthcare professionals, are unfamiliar with **peritoneal dialysis**.

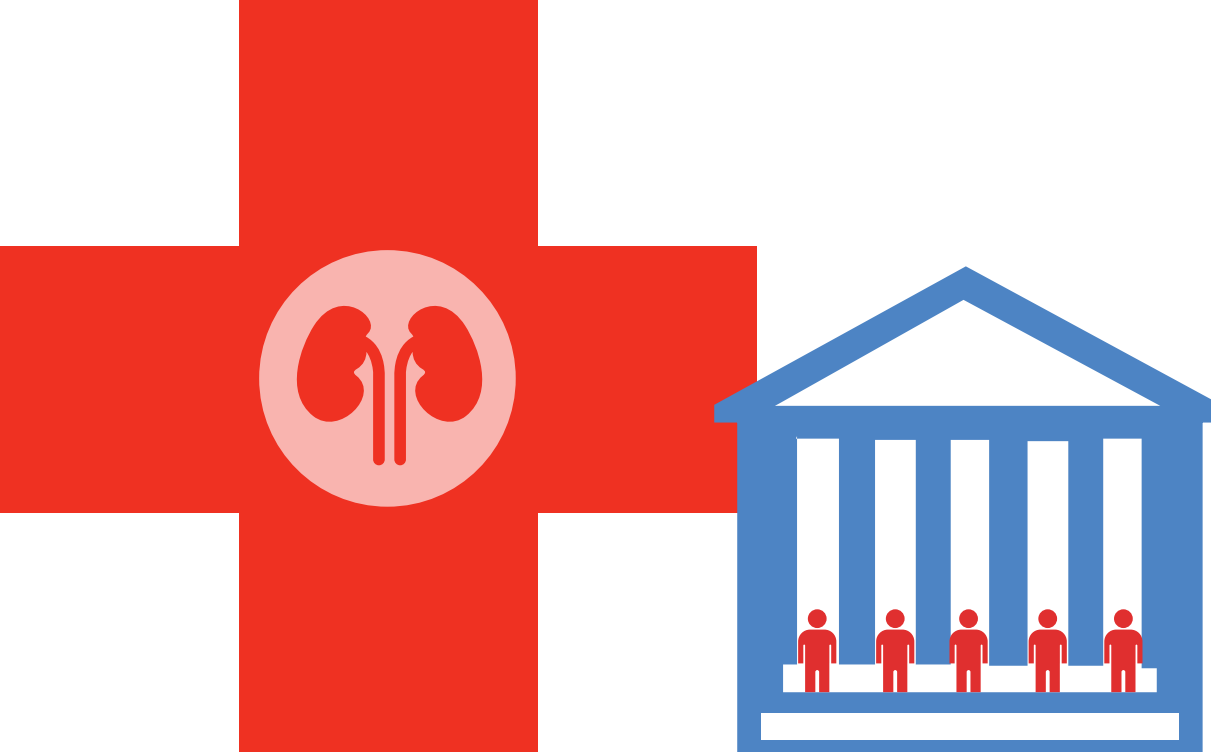
This can be a problem if you need to go to the emergency room or hospital. You may hear stories from peritoneal dialysis (PD) patients like: "No one knew what peritoneal dialysis was; they thought my catheter was a feeding tube" or "The nurse didn't put on a mask, and no one knew what a cyclor was." Consider this lack of knowledge a testament to the fact that many peritoneal dialysis patients stay at home because they are doing well!

To avoid problems in the hospital or emergency room, you or your family may need to educate others. The professionals in the hospital are doing their best, but if they see peritoneal dialysis patients infrequently, your guidance will be appreciated. Remember that you are the most knowledgeable person regarding your treatment.

IMPORTANT THINGS TO REMEMBER when preparing for a hospital visit



1. Identify your hospital of choice and find out what floor or unit does PD.
2. Alert your dialysis unit when you go to the emergency room or are hospitalized.
3. In the hospital, ALWAYS identify yourself as a peritoneal dialysis patient at each stop along the way, and to every new healthcare worker that you meet, even if you are there for a reason unrelated to your dialysis.
4. Provide healthcare workers with information regarding your dialysis: the name and phone number of your dialysis unit, nephrologist's name and your prescription.
5. When scheduled for a procedure, tell the doctor you are on PD. Also inform your dialysis healthcare team. Some procedures require prophylactic antibiotics and for your abdomen to be empty.
6. If you're uncomfortable with how your treatment is being administered, speak up! If necessary, ask that your nephrologist be called.
7. If you are having problems related to your dialysis treatment, first call your dialysis unit and try to get treatment there if possible.
8. Consider getting medical ID jewelry with important information for treatment and contact information for your healthcare team.



AFFORDABLE CARE ACT

& DIALYSIS PATIENTS

You may have heard about the Affordable Care Act (ACA), but more likely you've heard it called "Obamacare." Whatever you call it, it is now the law of the land and requires everyone — adults and their children — to have health insurance or pay a penalty.

But the law isn't just about requiring people to buy insurance; it is about making health insurance cover the services people need most and keeping them from financial ruin in the face of an unexpected medical event. In that way, it is not unlike the Medicare End Stage Renal Disease (ESRD) benefit enacted in 1972 that

allowed more people with kidney failure an affordable way of receiving dialysis treatments and kidney transplants. Prior to the Medicare benefit, most people with kidney failure died because access to dialysis and transplantation was limited.

Most Americans with kidney failure are enrolled in Medicare today, regardless of their age, and don't need to purchase health insurance in the Marketplace. However, you may still have questions about ACA and how it may or may not help you and your family. Here's what you really need to know if you are a dialysis patient.

WHAT YOU NEED TO KNOW:



Q If I have Medicare do I have to buy health insurance in the Marketplace?

A No, there is no need for you to purchase additional health insurance through the Marketplace if you are covered by Medicare, since it is unlikely to offer you additional benefits above what Medicare covers. In addition, it is illegal for an insurer to try to sell you a health insurance plan through the Marketplace if you already have Medicare.

Q I have Medicare, but I do not have any supplemental coverage. Can I buy supplemental coverage in the Marketplace?

A No, Marketplace plans are for primary health insurance only and will not pay the 20% coinsurance on medical treatments.

Q I have Medicare, but my spouse and my children are uninsured. Will I have to pay a penalty if they don't get health insurance? Can we get financial assistance to help pay for insurance for them?

A Yes, if your family members do not have health insurance, you will pay a penalty on your 2014 income taxes. The penalty for 2014 is \$95 per adult, \$47.50 per child, or 1% of household income (whichever is larger) and increases in the following years. The good news is now there are more affordable options for your family through the Health Insurance Marketplace. Also, financial assistance is available if your family makes between 100-400% of the poverty level. Your family members may also be eligible for the state Medicaid and state Children's Health Insurance Program.

Q I don't qualify for Medicare. Can I get coverage in the Marketplace?

A If you are in the U.S. legally, but have not earned enough credits to qualify for Medicare, you will be able to purchase coverage in the Marketplace, and may qualify for tax credits and subsidies.

Q How does the ACA help me pay for my prescription medications?

A If you have Medicare Part D, the coverage gap also known as the "donut hole" is being phased out over the next 6 years, so that you have to pay less out-of-pocket for your medications when you reach the coverage gap threshold. In 2014, you will pay 50% of the costs of your brand name drugs and 79% of your generic drug costs when you reach the "donut hole," but by 2020 the "donut hole" will be closed and you will pay 25% of your prescription drug costs (brand and generic).

In sum, if you have Medicare you do not need to enroll in the Marketplace. The Affordable Care Act does not change your Medicare coverage except that it helps you pay for your prescription medications by closing the Medicare Part D "donut hole."

For more questions and answers about the Affordable Care Act for dialysis patients, visit us online at:

kidney.org/kidneyliving

or contact us at:

855.NKF.CARES
nkfcare@kidney.org





National
Kidney
Foundation™

Kidney Walk

Each year, more than 75,000 people lace up and join the National Kidney Foundation for Kidney Walks around the country. Kidney Walk is the nation's largest walk to fight kidney disease. Held in nearly 100 communities, the event raises awareness and funds for important programs that educate and support patients, their families and those at risk for kidney disease.



Walking with others affected by kidney disease is a great way to get involved in your local kidney community, and get some fresh air and exercise! So find a Kidney Walk near you, and form a team with your family, friends, and other dialysis patients from your center. Sign up today! kidneywalk.org



“

When I did my research, I knew that NKF was a charity that I wanted to support. I looked at how they were using their finances and the work they were doing and that gave me confidence to get involved. Kidney Walk is a fun and supportive atmosphere.

I got to lead the warm-up workout and share my story with others who are going through the same thing. It's a great opportunity to interact with, and encourage each other in our struggles. ”

— LaMonte Reed,
Dialysis Patient





Weathering the Winter ... It's about **Being Prepared!**

By Lisa Hall, MSW, LICSW—Patient Services Director, Northwest Renal Network

For dialysis patients, winter weather can create additional challenges, so it's important to be prepared. Whether you're on in-center hemodialysis, peritoneal dialysis, or home hemodialysis, your dialysis center is responsible for helping you make an emergency plan.

Here are some important things you should talk to them about:

- Emergency phone numbers for the dialysis center and local agencies
- Where to get dialysis treatment if your center is closed
- Emergency diet and fluid restrictions
- Medicines and supplies to keep at home
- Transportation options if your regular ride is not available
- If you dialyze at home: Keep a two-week stock of dialysis supplies
- Check expiration dates regularly and replace when needed.
- Register with local water and power companies as a dialysis patient for priority restoration of service.



Visit the National Kidney Foundation website at www.kidney.org/help for other emergency planning resources, including how to find out which centers are open during emergencies.

If you're a peritoneal dialysis patient, you should also talk to your dialysis team about:

- Including an antibiotic for peritonitis in your emergency medication pack. If a disaster occurs, it may be difficult to maintain a clean environment and your risk of peritonitis may be higher.
- If you do Automated Peritoneal Dialysis (APD), you should also know how to do manual exchanges (CAPD) in case you are unable to use the cycler.
- If you are an APD patient and you lose power while dialyzing, follow the instructions given to you by the APD training staff for discontinuing dialysis in an emergency situation.



Sticking to
your New Year's
resolutions can
be difficult.

Dining Smart

5 tips for dining out

1

Restaurant choice

It is important to choose a restaurant that offers foods that you can eat. Restaurants that serve a wide variety of foods make it easier to dine out. Try calling ahead to ask some questions about the menu or check the restaurant's website in advance.

2

Serving size

Eating a sensible serving size is important for calorie control. You can eat half of a serving and take the other half home, share an entrée with a friend, or order two appetizers as a meal instead of one large entrée.

3

Take medication

You may be on medications that you should take with or after a meal. Bring your medications with you. Set an alert on your phone or watch to remember to take them. Remember that it is important to take your phosphorus binders *with* your meal!

4

Salt sense

Ask that foods be prepared without salt or MSG and avoid cured, pickled, or smoked foods. Ask for sauces and gravies on the side. Skip the soup and order a green salad instead. Ask for celery, carrot sticks, or lettuce instead of pickles and olives. Don't use the salt shaker.

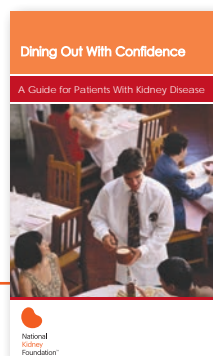
5

Cut the fat

Ask to have your foods baked, broiled, roasted, steamed, or grilled (instead of fried or sautéed). Trim all visible fat from meat and remove poultry skin. Skip creamy sauces or gravies and use little or no butter on your food. For salad, ask for oil and vinegar on the side.

for more info

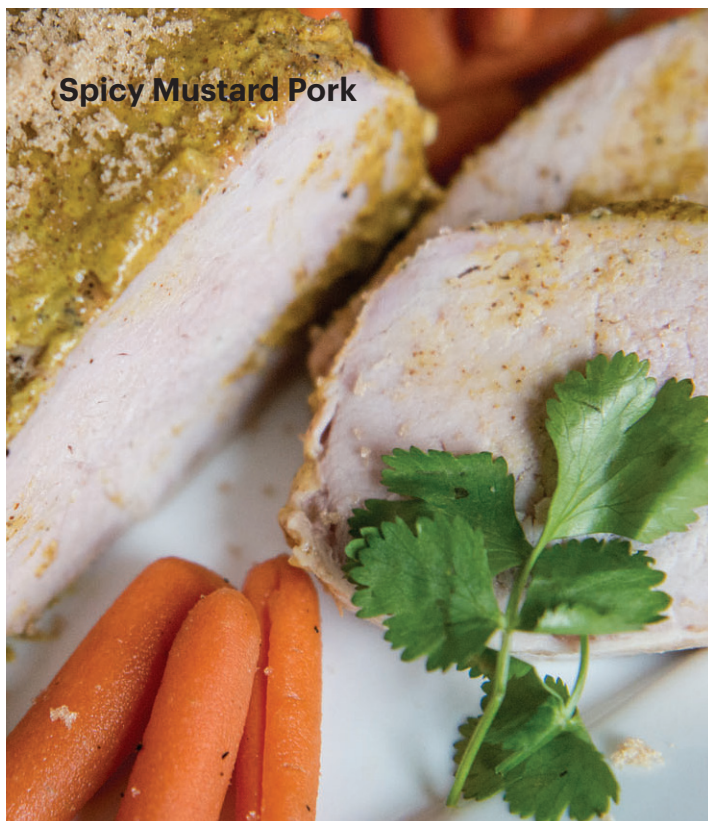
Call NKF Cares at **855.NKF.CARES** (855.653.2273) and ask about our free brochure, *Dining Out with Confidence*. You can also visit us online at kidney.org/kidneyliving.



Poblano Soup



Spicy Mustard Pork



Three Pepper
Quiche





Warm up your winter with

Hearty Dishes

Poblano Soup*

Serves 5 (½ cup per serving)

INGREDIENTS:

- ½ stick butter
- ¼ onion, diced
- 3 cloves garlic
- 3 poblano peppers
- ¼ cup all-purpose flour
- 2 cups low-sodium vegetable or chicken stock
- 1 cup low fat milk
- 1 cup water
- ½ teaspoon salt
- ½ teaspoon black pepper

DIRECTIONS:

1. Place peppers and garlic on a baking sheet and roast under broiler 5 minutes, or until peppers are blackened and garlic is soft. Turn as needed.
2. Place peppers in plastic bag and seal the bag.
3. After 10 minutes, remove peppers and peel away skin.
4. Seed and quarter the peppers.
5. Melt butter in saucepan.
6. Add onions. Cook until translucent.
7. Add flour. Whisk until mixture is thick and slightly darkened.
8. Add stock, milk, and water while stirring.
9. Add peppers, garlic, salt, and black pepper. Then puree mixture to the consistency you prefer.

ANALYSIS:

Calories: 189
Carbohydrates: 17g
Protein: 6.2g
Fat: 11g

Sodium: 397mg
Potassium: 449mg
Phosphorus: 110mg

Spicy Mustard Pork

Serves 10 (3 ounce servings)

INGREDIENTS:

- 2 pound boneless pork tenderloin
- ½ teaspoon pepper
- 3 tablespoons low-sodium mustard
- ⅓ cup brown sugar
- ½ cup water

DIRECTIONS:

1. Preheat oven to 425°F.
2. Trim fat from pork and sprinkle pepper on it. Bake in oven for 30 minutes.
3. Combine mustard and brown sugar and put on pork. Reduce oven temp to 375° for 45 minutes until cooked through (to 160°F).
4. Enjoy!

ANALYSIS:

Calories: 77
Carbohydrates: 2g
Protein: 12g
Fat: 2g

Sodium: 79mg
Potassium: 200mg
Phosphorus: 125mg

Bon appétit!

Visit Kidney Kitchen online for more recipes:
www.kidney.org/patients/kidneykitchen



3 Pepper Quiche

Serves 8 (⅓ quiche)

INGREDIENTS:

- 1 tablespoon margarine
- 1 green pepper, cut in strips
- 1 sweet red pepper, cut in strips
- 1 sweet yellow pepper, cut in strips
- 4 eggs or 1 cup low-cholesterol egg substitute
- ½ cup liquid non-dairy creamer**
- ½ cup water
- ½ teaspoon basil
- ⅓ teaspoon cayenne pepper
- 9-inch pie shell, unbaked

DIRECTIONS:

1. In a large skillet, sauté pepper strips and margarine until soft but not limp.
2. In a bowl, combine eggs or egg substitute, creamer, water, basil, and cayenne pepper.
3. Spoon peppers into unbaked pie shell. Pour egg mixture over peppers.
4. Bake at 375°F for 50-55 minutes until a knife inserted in the center comes out clean.
5. Let stand for 10 minutes before serving.

ANALYSIS:

Calories: 201
Carbohydrates: 14g
Protein: 5g
Fat: 14g

Sodium: 222mg
Potassium: 163mg
Phosphorus: 50mg

*Note: If you are on a fluid restriction, talk to your doctor or dietitian about fluid and soup.

**Note: Check with your dietitian to determine if the non-dairy creamer you will use is low enough in phosphorus.



Q What should I tell my family and friends about my kidney disease? I don't want to burden them and they probably won't understand. Do they need to know what I'm going through?

A Many people feel overwhelmed or nervous at the thought of talking to family and friends about kidney disease and being on dialysis. They may worry that people will view or treat them differently. It's important to realize that your family and friends care about you, are there to support you and want to help you.

When a family member develops kidney failure, the whole family is affected, even if they don't all show it. Family members are likely to experience some of the same feelings as you. They may be worried about how you are coping, but not know how to express their concerns. It can be helpful to share your feelings with others, to ask for help and tell others what you need.

Many people aren't familiar with kidney disease and dialysis. Although people who aren't on

dialysis can never really know exactly what you're feeling, they do care about you and their support will help you live a healthier, fuller life. It may be helpful to talk to some of your family and friends about your experiences. If you need help with this, ask your social worker or other members of your healthcare team for advice on how to start the conversation, or call the NKF Cares Patient Help Line at toll-free 855.NKF.CARES or 855.653.2273 to request free brochures to share with family or friends.

There is no right or wrong way to talk with your family and friends about kidney disease and being on dialysis. Most important is maintaining a healthy support system by talking with the people close to you. Even your closest family members cannot read your mind, so it's important to tell them how you feel!

TALKING TO CHILDREN



Do you need help answering questions from your children about your kidney disease? Please visit or contact us.

[kidney.org/kidneyliving](https://www.kidney.org/kidneyliving)

855.NKF.CARES

nkfcares@kidney.org



what are your New Year's

RESOLUTIONS?

It is nine years since I started on dialysis, and my New Year's resolution is an ongoing one — to maintain a healthy lifestyle by continuing to exercise and eating healthy. I have come to understand that in order to experience optimum wellness being a dialysis patient, one must follow guidelines pertaining to diet, including fluid intake.

– **Debra B.**

When I am feeling rotten after a treatment, I listen to music. I love jazz and somehow it always brings me out of the dumps. I'm 87 but still go dancing twice a week. Music, dancing and watching my fluid intake is keeping me alive.

– **Charles M.**

My New Year's resolution for staying healthy while on dialysis is to exercise more and make better food choices. I am going to sign up with a friend for a dance class like Zumba or water aerobics. This way I will be accountable to someone. I can't disappoint a friend by not showing up. I'm excited for this year ahead!

– **Angela S.**

I am currently enjoying my third year of successfully losing weight. I have lost 135 pounds for transplant. For the New Year I am planning to continue to stay healthy and strong by walking every day 30-45 minutes and to stay strong for myself, my family and those I love. Having kidney failure has taught me a lot about myself and what I need to do to stay healthy. I keep my eye on the prize and I know there is a "light" at the end of the tunnel. For those who think it's not possible.....IT IS! Just make a plan and DO IT! Best wishes for a happy, HEALTHY and GREAT New Year!

– **Steve F.**

I started dialysis in July 2013. I have had some problems with depression. Physically I feel better since going on dialysis but mentally it has been hard. I plan to keep busy with bowling, church work and friends and to eat healthy.

– **Ruth J.**

I will get in better shape. I will try better recipes. I will help and encourage someone else on dialysis to get or stay on the right track.

I will have more fun with my family.

– **Lisa B.**

I will continue to stay on my kidney diet and add new recipes that are healthy for me. I will exercise more.

– **Harriet P.**

My New Year's resolutions this year are to stay positive, keep doing my daily routine and whatever else it takes to keep me healthy. I was born with chronic kidney disease and have had 2 transplants that failed. I was on peritoneal dialysis for 9 years after I lost my first transplant. Since my second transplant failed I've been on hemodialysis for the past 8 years. I'm 26 now and throughout my life, I learned that no matter how hard things get, don't lose hope because no matter how challenging life can be, the obstacles will get harder through your journey but you have to tell yourself mentally that nothing is impossible.

– **Matthew M.**

I want to switch to home hemo so that I can have more control over my treatment and be more available to my family.

– **Kevin S.**

National Kidney Foundation

30 East 33rd Street
New York, NY 10016

Non-profit Org.
US Postage
PAID
National
Kidney
Foundation



Electronic Service Requested

Help is at hand



Because of support from generous donors like you, all of our programs and services are offered free of charge.

Please consider making a donation to NKF today with the enclosed donation envelope or online: **www.kidney.org/support**

You are not alone.

Learn more at
www.kidney.org | 800.622.9010



National
Kidney
Foundation™