



National
Kidney
Foundation®

kidney living®

Spring 2015

Issue 10

BREAKFAST

START THE DAY RIGHT!

IT'S UP TO YOU

**CHOOSING A
DIALYSIS CLINIC**

GETTING ENOUGH?

**HOW MUCH DIALYSIS
YOU REALLY NEED**



EDITORIAL BOARD

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®

A MAGAZINE FOR PEOPLE ON DIALYSIS

Be the captain of your own ship!

I have had the unique opportunity to work with kidney patients from all walks of life, as well as with the staff who provide them with care each day.

In doing this work, it has become very clear that patients who are involved in their care tend to be happier and healthier. More and more we are hearing about patient engagement. But what does that mean?

Simply put, patient engagement means being involved. It means using your voice to express your concerns, needs, and goals with your treatment team. One great way to do this is by attending your annual Plan of Care meeting. During the meeting, you will have the opportunity to ask questions about your treatment and to provide input to ensure that the plan meets your needs.

In this issue, we talk about different types of medication, questions you should be asking your treatment team, and most importantly, how you can improve your overall quality of life by being more involved. Remember, it's your life and your care! Let your voice be heard.



Eileen Boyte

Eileen Boyte, MSW
Professional Editor, *Kidney Living*
Patient Services Director,
End Stage Renal Disease (ESRD)
Network 18

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 a magazine for people on dialysis published by the National Kidney Foundation (NKF). Opinions expressed do not necessarily represent the position of the NKF or its sponsors. The NKF reserves the right to edit all articles. Please contact the NKF for article submission guidelines or permission to reprint articles.

© 2015 National Kidney Foundation, Inc. 01-65-6882_ABF

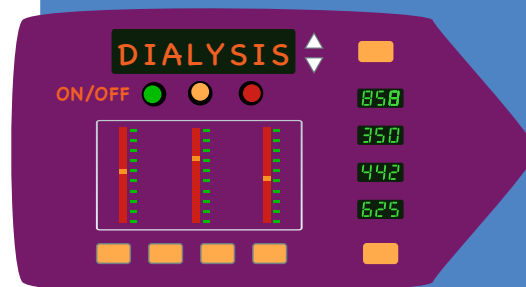
How do you choose
your dialysis center?

SHORT
DISTANCE
DRIVE

HOME
DIALYSIS
TRAINING

Your treatment,
your choice!

6



What's in this Issue?



FEATURE ARTICLE

- 4** My Rights and Responsibilities

IN EVERY ISSUE

- 9** Ask Your Healthcare Team

My doctor says I need to increase my time on dialysis. How can I not be getting enough when I am already on the machine for 3½ hours, three times per week?!

- 12** Kidney Kitchen

Breakfast Recipes — Start your Day Right!

- 14** kidney living Voices

How did you adjust to following the dialysis diet? Do you have any tips for someone new to the diet, or having trouble sticking with it?



MY **RIGHTS** & **RESPONSIBILITIES**

It's so important to be actively involved in your healthcare! Understanding your rights and responsibilities as a patient will help ensure that you and your healthcare team create the right treatment plan for you.

While quality care and privacy are things you should expect and, in fact, demand from providers, there are also things you need to do to help your healthcare team to be able to provide you with exceptional care.

YOUR RIGHTS



- Receive high-quality healthcare.
- Receive information from your healthcare team in words that you can understand.
- Be treated with dignity, respect, and consideration.
- Expect that treatment will be tailored to your individual health needs.
- Expect that your personal medical information will be kept confidential.
- Receive a full explanation of all treatment options for kidney disease, including their advantages and disadvantages.
- Receive counseling and care by a doctor, dietitian, social worker, and nurse on a regular basis.
- Be informed by the dialysis facility about their emergency plan in case of a disaster (e.g., snow storm, fire, loss of power).
- Expect the dialysis facility to employ skilled staff and provide safe, clean, comfortable, and professional surroundings.
- Expect the facility to make every effort to make you comfortable and give you your treatment on time, according to a schedule that meets special needs whenever possible.
- Expect the facility to monitor the quality of treatment and equipment according to regulations.
- Refuse any drugs, treatments, or procedures offered to you while accepting full responsibility for the medical outcomes of your refusal.
- Be informed about your financial responsibilities after Medicare or Medicaid and/or other health insurance coverage.

YOUR RESPONSIBILITIES



- Be informed and learn as much as you can about your kidney disease and how it is treated.
- Talk to your healthcare team about any concerns regarding your treatment.
- Follow your treatment plan designed by your healthcare team to meet your individual needs.
- Find out about the other services and referrals your healthcare team recommends.
- Make every effort to be on time for your scheduled dialysis. Tell the dialysis facility ahead of time if you are unable to attend your next treatment.
- Follow the facility policies and procedures that have been developed to provide safety and quality of care to all patients.
- Treat other patients and staff members with respect, dignity, and consideration. Never threaten others, act in a violent manner, or cause any physical harm.
- Make every effort to pay your bills for care from the dialysis facility and doctor(s). Obtain all insurance you are eligible for such as Medicare, Medicaid, or private insurance. Maintain active insurance coverage and alert your healthcare team of any changes in coverage.



If you have questions or concerns about the quality of care in a particular facility, you should contact the ESRD Network in your area. Find yours by visiting: esrdnetworks.org

Learn more about your Rights & Responsibilities: kidney.org/kidneyliving



TIPS FOR CHOOSING A DIALYSIS CLINIC



Choosing a dialysis clinic that is right for you is important. If you are a new patient, traveling, or looking to transfer, this choice can seem overwhelming. Here are some key factors to consider when choosing a clinic.



KEY FACTORS TO CONSIDER

DISTANCE

How important is being close to your facility? Do you have reliable transportation to get to your treatments? How far are you willing to travel to receive treatment?

NEPHROLOGIST

Does your doctor see patients at this facility? How important is it to you to continue to be treated by your current nephrologist?

HOME DIALYSIS

Are you interested in home dialysis? Does the clinic offer peritoneal dialysis or home hemodialysis? Nocturnal dialysis?

SCHEDULE AVAILABILITY

Does the clinic offer a dialysis schedule that fits your needs? Are there openings for new patients on those shifts?



In addition to choosing a dialysis facility based on your preferences and needs, there are many ways to evaluate the quality of care provided by a dialysis center. CMS (Centers for Medicare & Medicaid Services) collects statistical data on each dialysis center through the CROWNWeb system and it is publicly reported through these quality programs:

Dialysis Facility Compare (DFC) — is a website that provides you with a “snapshot” of a facility, which may help you make a few useful comparisons. Dialysis centers are assigned 1 to 5 stars by comparing the health of the patients in their clinics to the patients in other dialysis facilities across the country.

Quality Incentive Program (QIP) — promotes high-quality services in outpatient dialysis. The first of its kind in Medicare, this program changes the way CMS pays for the treatment of patients with kidney failure by linking a portion of payment directly to facilities’ performance on quality of care measures. Each dialysis facility receives a numerical score on their performance, which must be displayed prominently in the dialysis facility so patients can see it.

These quality ratings/scores do not take into account factors like cleanliness, attentiveness of the dialysis facility care team, compassion, or how satisfied patients are with the care they receive. It is therefore important to remember that you are the best judge of your own care. Some things you might want to consider are:

- How well does the dialysis facility staff listen to you and address your needs?
- How well do you feel during and after dialysis?
- Do you receive clear and understandable advice from the staff about what your role is in improving your own health?
- Is the facility adequately staffed with experienced, trained professionals?
- Is the staff compassionate? Attentive? Respectful?
- How would you rate the overall cleanliness of the facility?
- Does the facility offer a time and day for treatment that meets your needs? Is the schedule flexible?
- Does the facility offer home dialysis?

LEARN MORE

QIP/DFC and find
your facility’s score:

[www.medicare.gov/
dialysisfacilitycompare/](http://www.medicare.gov/dialysisfacilitycompare/)

Choosing a
dialysis clinic:

kidney.org/kidneyliving

CROWNWeb:

[http://projectcrownweb.org/
help/patients-and-crownweb/](http://projectcrownweb.org/help/patients-and-crownweb/)

ENGINEERING KIDNEYS



Polycystic kidney disease (PKD) is a devastating condition that affects over 12 million people. Benjamin Freedman, PhD, an Instructor in Medicine at Brigham and Women's Hospital and Harvard Medical School, is working to stop PKD before it damages the kidneys.

Dr. Freedman's research, funded in part by a Young Investigator's Grant from the National Kidney Foundation, focuses on modifying stem cells from patients with PKD. Differentiating these cells into kidney tissue will allow the creation of models to understand PKD better. Eventually, these PKD kidney cells will serve as testing grounds to assess safe medication doses for human cells and tissues before taking new treatments to clinical trial.

Dr. Freedman became interested in stem cells and regeneration while studying biochemistry at the University of Pennsylvania. He began applying his knowledge to kidney disease because both his grandfather and his uncle were on dialysis. That interest took him to the laboratory of Dr. Joseph Bonventre in Boston, where he trained as a fellow from 2010-2013, and began his current research.

Initial papers on the process of generating PKD cells have already been published, and Dr. Freedman believes that drug screens for PKD could start within the next five years. "We will first see the use of these kidney-in-a-dish models as a way of analyzing toxicology," he said. "The biopharmaceutical companies are going to be very interested in looking into these stem cell-derived tissues for researching new therapies."

*If we learn to
do this properly,
we'll find new
ways to create
kidneys...*

Dr. Freedman's research is also forming the background for a larger project — regenerating kidney cells from PKD patients, editing those cells to remove the PKD mutation, and putting these disease-free cells back into patients. This process essentially creates

immunocompatible kidneys that could be designed on demand without the risk of rejection.

"From a broader level, whatever we learn about making kidney tissue will also be relevant to the kidney patient population as a whole," Dr. Freedman said. "If we learn to do this properly, and it's safe and compatible, we'll find new ways to create kidneys for all patients with kidney failure."

Dr. Freedman believes his work hinges upon continued collaboration and support from patients, researchers, and foundations alike. "I'm very thankful to the National Kidney Foundation for supporting this research," said Dr. Freedman. "They gave me my first independent grant as a faculty member. It's a tough time for researchers, and it's important that we communicate with the public and get the word out. These are hard problems to solve. They aren't going to be solved overnight, or by a single individual. They will be solved by a community coming together to figure out the best approach to tackling a problem."



My doctor says I need to increase my time on dialysis. How can I not be getting enough when I am already on the machine for 3½ hours, three times per week?

It can be very frustrating to hear that you need to stay on the dialysis machine for a longer period of time. Although everyone sits in the same chairs and is using the same machines, your treatment is actually a specific prescription crafted uniquely for you by your doctor. Your blood work is drawn every month to see how well your dialysis treatment is working. These lab tests help your healthcare team determine whether you are getting the right amount of dialysis. The results will alert them if changes need to be made:

Kt/V (pronounced “kay tee over vee”) is a measure used to help your healthcare team know if you are getting the right amount of dialysis. Receiving the right amount is important to your overall health. Depending on what type of dialysis you are on, your goal Kt/v may vary. Kt/V should take into account any remaining kidney function you may have.

Hemodialysis patients receiving dialysis three times a week should have a Kt/V of at least 1.2. Kt/V is measured by routine blood tests, which will be drawn during dialysis treatment.

Peritoneal dialysis (PD) patients should have a Kt/V of at least 2.0. In PD, Kt/V is measured by collecting drained dialysate along with any urine you produce in a 24-hour period. For peritoneal dialysis patients the Kt/V is usually measured quarterly.

Ask your doctor what your specific goal is and what can be done to make sure you reach it. There are many factors that affect Kt/v, such as having an access that is functioning well, using an appropriate sized dialyzer, and length of time spent on the dialysis machine.

Urea Reduction Ratio (URR) is another measure of how well your hemodialysis treatments are working to clear wastes from your blood. It is calculated based on blood tests but not urine collection. Your target URR should be 65 percent or higher.

Talk with your healthcare practitioner about any concerns you have about your treatment. Ask for a copy of your labs each month. If you are experiencing any cramping, nausea, or vomiting, or if you believe you have lost or gained weight, let your healthcare team know.



Your Family Tree

what your roots reveal
about your health

How PKD affected my family

By Alexis Meza



My Friday morning started out the same way it always did. I woke up, showered, and got ready for my class at 11:00 a.m. But, as I was heading out to class, I received a text message from my mother saying she was heading to the emergency room with my father. The doctor had called back about his test results and was sending him straight to the hospital.

My heart beat fast as I scoured over every word in the message. I did not know what was going on. The drive to the hospital seemed like it was taking forever and the reality of the situation had not quite sunk in.

When I arrived at the hospital, I found out my father had been diagnosed with kidney failure. He hadn't known there was a problem with his kidneys, but tests revealed polycystic kidney disease. The doctor told him he would need to start dialysis or get a kidney transplant.

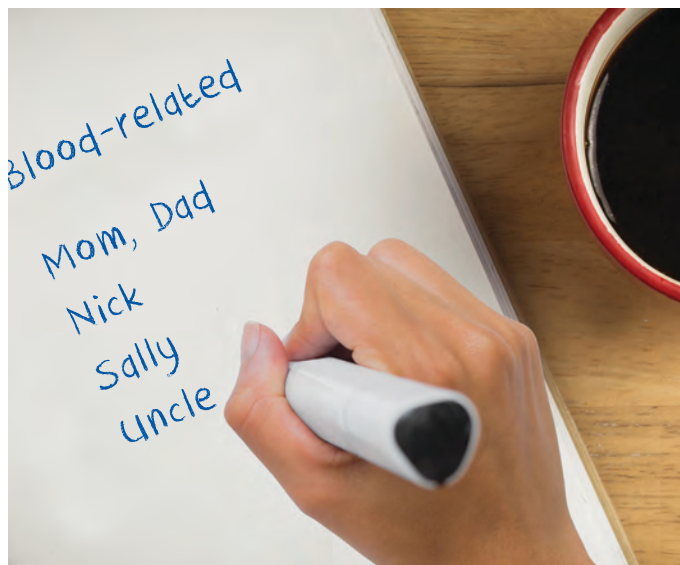
Polycystic kidney disease (PKD) is an inherited disease that causes numerous cysts to grow in the kidneys.

These cysts are filled with fluid. If too many cysts grow, or if they get too big, the kidneys can become damaged because these cysts slowly replace healthy kidney tissue, which reduces kidney function and leads to kidney failure.

For my family, things have never been the same since that day at the hospital. It has been challenging for us to adapt to the new routine. Changing the way my mother cooks at home has been one of the main challenges, since my dad always craves Mexican food or other dishes he is not allowed to eat anymore. We've had to learn about reading food labels to make sure he gets the nutrients he needs, while avoiding too much of the ones that could harm him.

My father now goes to dialysis three times a week for four hours each time. "I feel better and have more energy," my father says. "Going through this experience has taught me that taking care of your body is very important."

PKD not only affects the person, but the family as a whole. Having a support system is important not just for PKD patients, but for anyone on dialysis. It is important to be informed about family history. As the daughter of someone with PKD, I worry about inheriting this disease, or passing it along to my children if I decide to have them one day. It's also important to learn what steps you can take to live a healthier lifestyle. As a dialysis patient, you can encourage your family to learn more about their risk for kidney disease and get tested.



1. MAKE A LIST.

Make a list that includes all the blood-related members of your family. Include your grandparents on both sides of the family, your parents, aunts and uncles, and siblings.

2. ASK ABOUT ANY MAJOR ILLNESSES, HOSPITALIZATIONS AND CAUSES OF DEATH.

A family history of dialysis or transplantation will give you a clue that kidney disease may run in your family. For any deceased family members, record their age at death and cause of death. If any relatives appeared healthy but died suddenly, mark that down to discuss with your doctor.

3. LEARN YOUR RISK FACTORS.

A risk factor makes you more likely to develop a particular disease or health condition. In general, risk factors can be other diseases, traits such as your age or race, or behaviors such as smoking. Genetic risk factors refer to those that could be passed down through your genes. If kidney disease, diabetes, or high blood pressure run in your family, it's important to make a note

of them because these place you at increased risk for developing kidney disease. If you are African American, Asian, Hispanic, American Indian, or Pacific Islander, you are at increased risk for kidney disease.

4. SHARE THIS INFO WITH YOUR DOCTOR.

Knowing your risk factors and sharing them with your healthcare provider helps to make sure that you are screened for diseases that may be transmitted genetically in your family. There is no universal blood test that screens for all genetic diseases, so you must speak up about your health history to help guide your doctor where to look.

5. GET TESTED.

It may seem scary, but there are ways to help prevent or minimize the impact of hereditary diseases. These might include making lifestyle changes or further testing for detection and treatment. Screening for kidney disease involves blood and urine testing. Certain kidney diseases, including polycystic kidney (PKD) disease and Alport's syndrome, can be specifically tested for in the lab.

Breakfast!



Recipes to Start your Day Right

Your doctor and mother are right: breakfast is the most important meal of the day! A healthy breakfast provides you with the mental and physical energy needed to carry out everyday tasks in a productive and timely manner. Studies show that eating a nutritious breakfast leads to increased energy, better weight control, and improved concentration. So get your day started with some of these tasty breakfast options!



Chicken Egg Bake Strata Serves 6

INGREDIENTS:

- 1½ tbsp unsalted butter
- ½ small onion (finely chopped)
- 1 stalk celery (finely chopped)
- 3 oz. asparagus (cut into 1-inch pieces)
- ¼ cup water
- 2 cups cooked chicken (shredded or cubed)
- ½ cup mayonnaise
- ¾ cup rice milk
- ¾ cup low sodium chicken broth
- 1 cup egg beaters

- ½ tsp black pepper
- 3 cups any style white bread (cubed 1 inch)
- 1 cup low sodium shredded cheddar

DIRECTIONS:

Melt butter in a frying pan over medium high heat. Add onion and celery; cook about 5 minutes. Add asparagus and water, cooking for about 3 minutes. Transfer to large bowl. Mix in chicken and mayonnaise.

Whisk rice milk, low sodium broth, egg beaters, and pepper in large bowl.

Layer half the bread cubes in a 9 x 13 greased baking pan, topping with half the chicken mixture. Top with another layer of bread, then chicken mixture. Pour egg mixture over the layered strata.

Bake covered with foil at 350° for 45 minutes. Remove foil and top with cheese; bake for another 15 minutes. Let rest for 5 minutes before serving.

ANALYSIS

Calories 258	Carbohydrates 12 g
Protein 24 g	Sodium 296 mg
Total Fat 12 g	Potassium 298 mg
Cholesterol 62 mg	Phosphorous 284 mg



Blueberry and Cream Stuffed French Toast

Serves 2

INGREDIENTS:

2 slices of white sandwich bread
(1½ inch thick)
½ cup egg beaters
1 tbsp liquid nondairy creamer
⅛ tsp vanilla
Pinch of cinnamon and nutmeg
1 cup blueberries
1 cup nondairy whipped topping

DIRECTIONS:

Cut bread in half along the diagonal for easier handling. Then cut a horizontal slit on the cut side for stuffing, making sure not to cut too deep to the crust side, thus creating a pocket for stuffing.

Prepare batter by whipping egg beaters, nondairy creamer, vanilla, and spices into a large bowl. Stuff bread with blueberries (each piece

should get about ¼ cup blueberries.) Dip stuffed bread into batter.

Cook stuffed bread on griddle at medium heat. After cooking, top with whipped topping.

ANALYSIS

Calories 266	Carbohydrates 35 g
Protein 9 g	Sodium 258 mg
Total Fat 10 g	Potassium 220 mg
Cholesterol 0 mg	Phosphorous 81 mg

Asparagus Quiche

Serves 6

INGREDIENTS:

1 tbsp unsalted margarine or butter
¼ cup onion, chopped
1 bunch asparagus (cut into pieces)
1 (9-inch) refrigerated, ready-to-use pie crust
1 tsp all-purpose flour
1½ cups egg beaters
¼ tsp black pepper
⅛ tsp dried dill

DIRECTIONS:

Cook butter and onion over medium-high heat until onion is translucent, for about 8 minutes.

Add asparagus and cook for about 3 minutes. Let mixture cool slightly. Dust one side of pie crust with flour and transfer to 9-inch pie plate, floured side down.

Press into pan, sealing any cracks. Trim edges, and place asparagus mixture on the bottom of the crust. In large bowl, beat egg beaters, black pepper, and dill, pour over asparagus mixture. Bake about 50 minutes. Cool slightly.

ANALYSIS

Calories 231	Carbohydrates 24 g
Protein 8 g	Sodium 277 mg
Total Fat 12 g	Potassium: 250 mg
Cholesterol 5 mg	Phosphorous 85 mg



Recipes courtesy of Rebekah Engum, RD, from her book *Creative Kidney Cooking for the Whole Family*.

How are you adjusting to the dialysis diet?



Do you have any tips for someone new to the diet, or having trouble sticking with it?

Relax and take a deep breath. Talk with your nutritionist at your dialysis center. Take your binders before meals. It's not easy because prior to dialysis you were on a protein restriction and when you started dialysis you needed to increase your protein intake. Just listen, read and research dialysis diets. *Bill M.*

I just decided that I'll have to do what I'll have to do. Since November I have switched to peritoneal dialysis, and have a little more flexibility in what I eat. It's all in the mindset and commitment. *Mark B.*

Keeping a list of foods I can have and ones I need to avoid on the refrigerator helps me and the whole family learn how I'm supposed to eat. It must be working. My labs are great! *Angelina W.*

I would recommend to new patients to eat a lot of fruits and vegetables and to prepare your own meals instead of buying out. *Glenda D.*

Listen to the nutritionist at your center. He or she will help you with the food groups and recipes. If you have Internet access use NKF's My Food Coach app. I have tried several recipes and they are delicious. Also, keep a positive attitude! I think of dialysis as my part-time job. I go in and get it done. *Eugenie L.*

My biggest concern was getting my family to understand that my dietary needs had changed once I became a dialysis patient. If you're not supposed to eat it DON'T BUY IT! And if you find yourself eating too much a day or two after you buy a weeks' worth of groceries, then don't buy a weeks' worth all at once. Get out and shop twice a week. The exercise is good for us. *Ruth A.*

Work closely with your dietitian, pay close attention to your labs! To do well on dialysis you need to change your whole way of thinking! You can do it! *Denny B.*

Two things that help me are journaling my food and liquid intake, and making special and attractive dishes. It is OK to spoil myself this way. It makes me feel happy. *Carolyn K.*

If you are on a modified or restricted diet, LEAVE THE SALT SHAKER alone, there are many low-salt or salt-free spices like Mrs. Dash, garlic powder, onion powder etc. out there that are flavorful. I eat a lot of fresh veggies and fruits too. I also have learned how to make my own BBQ sauces and gravies. *Casper R.*

I have been on dialysis for 30 years. For helping with the fluid restriction, frozen grapes are great. I know it sounds strange, but don't use a straw! You always drink more using a straw. Probably the most important tip is you have to read labels. Potassium chloride is hidden in all kinds of things. *Sherri P.*

For more **Kidney Living Voices** and to share your tips, please visit us online at kidney.org/kidneyliving

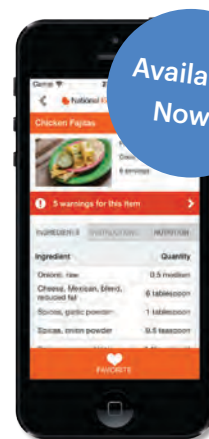


A new app from the NKF Available Now!

- **FIND** personalized recipes, ingredients and meals that fit your personal nutrition needs.
- **ADD** your own recipes and check the nutritional content of your favorite dishes.
- **BUILD** shopping lists and create a personalized recipe box.

You can access **My Food Coach by NKF** by downloading the app from your iTunes or Google Play store on your mobile device or online at:

<https://myfoodcoach.kidney.org>



Join our Advocacy Action Center

Use your voice to urge legislators to improve the care and quality of life of people with kidney disease.



www.kidney.org/takeaction



National
Kidney
Foundation®

30 East 33rd Street
New York, NY 10016
www.kidney.org



Electronic Service Requested



Together, we can help more people affected by kidney disease!

Our programs and services—including this magazine, are free of charge thanks to our generous donors.

Please consider making a donation today!

Use the enclosed donation envelope or go online at
kidney.org/support

Thank you!