FIT AND FABULOUS
START YOUR SPRING WORKOUT ROUTINE TODAY!

ADVOCACY MATTERS

SAVE BIG
ON KIDNEY-FRIENDLY FOODS
A PLEASURE TO SERVE YOU.

I am deeply honored to be the 23rd President of the National Kidney Foundation. In my career as a nephrologist, I have always focused on education. Recently, we formed the NKF Education Committee, which will provide guidance to the NKF about the most impactful ways to educate patients and professionals, and provide resources to help you live your best quality of life. I look forward to developing more tools and resources to empower patients and families affected by kidney disease.

NKF has always been committed to improving the lives of people with kidney disease. In addition, we are committed to increasing awareness of kidney disease, promoting early detection, improving treatment in primary care settings, and working together with nephrology providers. Clearly, we have a great deal of work to do. I look forward to pushing forward with these goals, but we will only be successful if we have people like you joining us in every step of the way!

There are many ways to get involved with NKF, and spreading awareness about kidney disease is something you can do right from your home. Talk with your friends and family about kidney disease and your experience. Join a Kidney Walk in your area or other local events. Follow NKF on social media and share our posts with your friends.

For more ways to get involved with our advocacy efforts, check out page 12 of this issue.

I am thrilled to be part the NKF team and to join you in the fight against kidney disease!

Sincerely,

Michael J. Choi, MD
NKF President
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Phosphorus and calcium work together to keep your bones strong. Over time, high phosphorus levels in your blood can lead to bone and heart disease. When your phosphorus level is high, the extra phosphorus starts to look for calcium in your body – and where does it look? In your bones. As calcium is taken from your bones, they become weak and brittle. This causes bone pain and a risk for fractured or broken bones.

Phosphorus is tricky because it is found in almost all foods. Phosphorus can be found in animal foods (meat, fish, chicken) and plant foods. Phosphorus found in animal foods is absorbed more easily by your body than phosphorus found in plant foods.

Also, sometimes phosphorus is found naturally in foods and other times it is added as a preservative. Added phosphorus can be found in fast foods, ready to eat foods, canned and bottled beverages, and most processed foods. Phosphorus from food additives is completely absorbed, so this is the most concerning type of phosphorus.

To make it even harder, phosphorus is not listed on food labels like other ingredients such as salt, fat, or protein. Instead, to find added phosphorus you have to look for words in the ingredient list that contain the letters “PHOS.” The closer to the beginning of the ingredient list, the more phosphorus.

It’s tricky, but don’t despair! The National Kidney Foundation (NKF) and your dietitian can give you a list of foods that are known to be high in phosphorus, as well as a list of foods that are better choices! And always remember to take your binders with every meal and with snacks. Also, if you change to a different type of dialysis, be sure to talk to your dietitian and healthcare team as a change in dialysis type may require adjustments to what you eat or drink. Talk with your dietitian about your personal diet needs and phosphorus goals.

Learn more about how to keep your phosphorus levels in check: kidney.org/kidneyliving
“Take your binders!” they say. “Don’t forget your binders!” they say. “Are you sure you’re taking your binders?” they ask. Many of us give a half-hearted, “yes of course I’m taking them”. When we know for a fact, there are a few meals we may have missed.

Some of us work jobs where we snack during our shift and forget to pop in a binder or two. I was working as a server and we’d snack throughout our shift, sneaking a cookie or whatever was out. But I wasn’t like everyone else, I couldn’t just snack without it having an effect on my phosphorus level.

I talked to my nephrologist and dietitian about this and they were very understanding that sometimes you don’t realize that even having a cookie here or there makes a huge difference. They suggested I put some binders in my apron and keep them with me throughout the shift.

But then there were days when I’d get depressed about my health and feel like I want to give up. So, I’d binge on all the wrong foods. I can’t believe I actually told my nephrologist, “but I just love mac and cheese”. And I’m sure he couldn’t believe what he was hearing judging by the look on his face. I wasn’t very smart for choosing food over my health. But when you’re depressed you aren’t thinking rationally. You’re at a place of “What’s the point in trying anymore if I’m not getting any results?”

Well, let me tell you the point. The point is you don’t want to have side splitting bone pain shooting up from your ankles to your hips with every step. You don’t want to agonize over the thought of just walking to the bathroom because each step feels like your hip will break at any moment. You don’t want to fear breaking your hip, like I do, and I’m only 27 years old.

Aside from bone pain, you don’t want to be threatened with having your parathyroid gland removed and being placed on calcium supplements for the rest of your life. And you don’t want to worry about missing a dose—because the moment you do, your calcium level drops so low that you feel numb all over and the bone pain comes back.

You want to know how I know all of this? Well, because I didn’t want to give up that mac and cheese until my PTH reached over 2000 and my phosphorus was as high as 10. My nephrologist struggled to control it with different medications but each month the level never came down.

At this point, my doctor recommended removing my parathyroid gland. I was faced with having yet another surgery, one that may have been avoided.

Learn from my mistakes. Eating what I liked may have given me temporary satisfaction but it cost me my parathyroid gland, and caused bone disease and a hip replacement. Trust me, it isn’t worth it.
Don’t Wait Self-Advocate!

Share Your Need for a Kidney Donor in Five Powerful Steps

By Risa Simon

You’ve been waiting months and months—perhaps several years, for a kidney transplant from a deceased donor. The meter’s running, the clock’s ticking and every day counts, but all you seem to do is wait.

You’ve been told to share your story and talk to your family and friends, but that’s not as easy as it sounds. How do you start the conversation and what do you say?

If you’re looking for answers, follow these five action steps to transform your storytelling skills into more meaningful and rewarding conversations.

STEP 1: SCRIPT IT!

Script your story as if you’re writing a movie about your life with kidney failure. List the events in the order they occurred and highlight key turning points. Include your struggles on dialysis. Identify our nation’s organ shortage and the life-threatening wait for a kidney from a deceased donor. Describe your hope in finding a living kidney donor who could end your wait and save your life. Make a long and short version of your story so you are prepared in all situations.

STEP 2: REHEARSE IT!

Rehearsing your story will calm nerves and create story-flow. Read your story and observe your feelings. Are they communicating what you are trying to say? Don’t worry if you feel awkward at first. It takes time to get into a “storytelling groove.” Remember, while rehearsing can make you a better communicator, it can also work against you if you attempt to memorize exact words. Use your script as a guide not as a mandate.

HOW DO YOU ASK FOR A KIDNEY?

If you need a kidney transplant, asking someone can seem impossible. We can show you how.

WHY THINK ABOUT GIVING ONE?

People everywhere are stepping up to help others live...family, friends, even total strangers. We can show you how—and why.
It’s time to take this assignment on the road. Start sharing your story with people you don’t know so you’ll worry less about the outcome. Consider store clerks, grocery baggers – even phone solicitors.

Now move on to all the people you do know. Don’t overlook business connections, like your hygienist, manicurist, hair stylist or barber, and bank tellers.

It’s important to deliver your story in written form too. Use email, social media, signage, and message boards. Remember, no one can offer to help if they are unaware of your need. Also, some may not want to donate, don’t give up. Be patient and accepting of people’s choices and keep telling your story!

Commit to sharing your story at least once a day with someone new. Make it a habit. Record your achievements and celebrate your efforts.

Want to increase effectiveness and listener receptiveness? Speak from your heart. You can get a palpable sense of “coming from the heart” by simply placing your hand over your heart when sharing your story. Test it out now.

If you can feel “it” – your audience will too.

If you’re asking for anything, you’re asking people to share your story. Let your heart guide you and your listeners will act in-kind. Your heart is the pipeline to abundant opportunity – claim it!

Push yourself to share your story on behalf of all those in need – not just you. Make it a duty and a privilege to maintain this commitment.

Risa Simon is a passionate patient advocate, motivational speaker and founder of the TransplantFirst Academy. This article contains excerpts (reprinted with permission) from the book: In Pursuit of a Better Life: The Ultimate Guide for Finding Kidney Donors.

STEP 3: DELIVER IT!

STEP 4: REPEAT IT!

STEP 5: HEART IT!

RECORD YOUR ACHIEVEMENTS

CELEBRATE YOUR EFFORTS

Risa Simon is a passionate patient advocate, motivational speaker and founder of the TransplantFirst Academy. This article contains excerpts (reprinted with permission) from the book: In Pursuit of a Better Life: The Ultimate Guide for Finding Kidney Donors.
TIPS TO SAVE

When Grocery Shopping for Kidney-Friendly Foods

Grocery shopping on a budget can be challenging. Follow the tips outlined below to get the best savings when shopping for kidney-friendly foods.

GO SHOPPING WITH A PLAN

• Know your budget and make your shopping list based on what you can afford.
• Plan a weekly menu before you go to the store so you buy only what you need. Check supermarket flyers, comparison shop, and plan menus based on the meat/protein that is on sale that week.
• Check your pantry and plan to use up what you already have at home.

• Clip coupons. Thursday and Sunday editions of local newspapers usually have them or you can look online. Sign up for store discount cards for additional savings. Also remember to save and use the coupons you receive at the store from past purchases.
• Be careful at food pantries as many options are full of sodium. Look for low sodium basics (rice, pasta, cereal) or purchase items for the rest of the family at the pantry and use the money you save on high protein, low phosphorus kidney-friendly foods from the grocery store for yourself!

• Eat before you go shopping to prevent impulse buying of foods not on your list.
• Only buy what you need to prevent throwing out food that may spoil before you use it.
• If you qualify, shop on “Senior Citizens Day” to take advantage of price breaks.

• Make sure you have a good supply of these less expensive proteins: eggs, low sodium-no phosphorus added canned tuna and chicken, dark meat chicken or turkey and chuck roast.
• Buy protein powder when it is on sale.
• Plan on shopping once a week or every other week and stick to your grocery list. The more often you go shopping the more likely you are to purchase foods you don’t need.
BE SAVVY IN THE GROCERY STORE

• In the store, shop for produce that is in season (such as strawberries, cucumbers, zucchini in the summer and apples, cabbage, or broccoli in the fall). Buy frozen or canned fruits (such as frozen peaches or berries, canned pears/pineapple/applesauce) or vegetables (frozen or canned without salt green beans/carrots/cauliflower/broccoli) when not in season.

• Visit discount supermarkets to stock up on basics and consider buying bulk or family portioned packages of meat, rice, beans, canned goods, frozen foods, and cooking oils at warehouse stores. You can divide the portions and store/freeze until it is needed.

• Corner markets and convenience stores are generally more expensive. Avoid them if you can.

• Many stores mark down produce, bakery items, and meats that will expire soon. Look for these items and plan to use them right away.

• Most grocery stores state the unit pricing as well as the regular price of an item on the in-store shelf label. This means you can compare the cost per ounce, pound, or other unit.

Use the unit price to find out which size package is the best deal based on the price per ounce, pound, or other unit. For example, the unit price of .05 makes this the better deal.

MINIMIZE WASTE ONCE YOU GET HOME

• Divide bulk items into meal-sized packages using freezer wrap/bags, for later use.

• When cooking, prepare enough for extra meals. Freeze leftovers not eaten within 3-4 days, then you’ll only have to thaw and reheat them.

• Spend some time cleaning/chopping a batch of fresh vegetables to use throughout the week. They’ll be all ready to eat as a snack, add to a salad, or cook as desired.

• Add chopped leftover meat/poultry/fish and vegetables to make a protein-packed frittata or omelet.

• Try the 3-in-1 dinner prep method: cook a large amount of meat/poultry (chicken, turkey, pork roast, beef) one night, and have enough to prepare multiple menu ideas for the next 2 nights as well. For example, roasting a chicken for dinner will give you leftovers to make a casserole the next night and chicken salad for lunch or a high protein snack during the week.

• Try some crock pot recipes if you have a slow cooker. You’ll save time in the kitchen at mealt ime, and leftovers will reheat easily. Some of the cheaper cuts of meat can be more tender if cooked in a crock pot or pressure cooker.

• Make sure to store leftovers safely and use quickly before they go bad. Put the date when they were prepared and stored on containers.

With proper planning and preparation, meals can be purchased and prepared affordably! Discuss your concerns with your dietitian and social worker who can assist you with local services. Ask about coupons for local farmer’s markets.
CORN SALAD

Makes 4, ½ cup servings

INGREDIENTS
2 cups fresh or canned corn
1 tsp celery seed
2 tbsps apple cider vinegar
2 oz green onion
1 oz canned pimento
¼ tsp salt
1 tbsp vegetable oil
1 tbsp granulated sugar
½ cup chopped green bell pepper
1 lemon

DIRECTIONS
If using fresh corn, shuck and boil corn 5-7 minutes. Drain and cool corn. Combine with remaining ingredients. Cover and chill. Add fresh lemon juice on top.

ANALYSIS
Calories: 121
Carbohydrates: 18 g
Total Fat: 4.6 g
Protein: 1.3 g
Sodium: 150 mg
Potassium: 51 mg
Phosphorus: 8 mg

SNOW PEA AND ORZO SALAD

Makes 6, 1 cup servings

INGREDIENTS
4 cups dry orzo
1 tbsp sesame seed oil
½ cup low-sodium chicken stock
1½ tsp horseradish
4 tsp Dijon mustard
2⅛ tsps spicy Szechwan five spice seasoning
2⅛ tsps sweet cooking rice wine
¼ tsp minced garlic
¼ cup lemon juice
8 oz snow peas*
2 large spring onions or scallions
8 oz boneless chicken breast, cooked and cubed

DIRECTIONS
Cook orzo according to package.

For the dressing: Mix together sesame seed oil, chicken stock, horseradish, Dijon mustard, Szechwan seasoning, sweet rice wine, minced garlic, and lemon juice.

For the salad: Place cooked orzo, snow peas (blanched and chilled), scallions and cooked chicken in a mixing bowl. Pour the dressing over the orzo mixture and toss before serving.

*If using fresh snow peas, place in unsalted boiling water; when the water returns to boil, remove from the heat, strain and place in an ice-water bath to stop the cooking process.

ANALYSIS
Calories: 653
Carbohydrates: 115 g
Total Fat: 6.6 g
Protein: 29.3 g
Sodium: 235 mg
Potassium: 151 mg
Phosphorus: 95 mg
ITALIAN BASIL CHICKEN SLIDERS
Makes 8, 2 slider servings

INGREDIENTS
1/2 medium onion
1 large granny smith apple
5 cloves garlic
1 cup all-purpose flour
16 oz ground chicken
4 large eggs
4 tsp ground basil
2 tsp each ground oregano and thyme
24 fresh basil leaves
16 white mini slider buns

DIRECTIONS
Peel and dice onion. Peel, core, and mince apple. Mince the garlic. Mix all the ingredients together, except fresh basil leaves and the buns. Make the meat mixture into 2 oz patties. Place the patties on an oiled baking dish. Bake the patties in a pre-heated 350°F oven for 20 to 30 minutes, until the patties are cooked completely through. Serve each patty on bun with 3 fresh basil leaves.

ANALYSIS
Calories: 368
Carbohydrates: 54 g
Total Fat: 8.9 g
Protein: 21.7 g
Sodium: 383 mg
Potassium: 413 mg
Phosphorus: 128 mg

HERB FISH STEAK
Makes 8 servings

INGREDIENTS
1 1/2 lb halibut
1 tbsp minced onion
1 tsp dry mustard
1/2 tsp oregano
1/4 tsp marjoram
1 pinch (1/16 tsp) black pepper
2 tbsps water
4 tsp fresh lemon juice
1/4 tsp paprika

DIRECTIONS
Place fish in a baking dish. Combine minced onion, mustard, oregano, marjoram, and black pepper with 2 tbsps water; let stand 10 minutes for flavors to blend. Add lemon juice. Spoon evenly over fish. Bake, uncovered, in a preheated 475°F oven for 17 to 20 minutes, or until fish flakes easily with a fork. Sprinkle with paprika. Serve with lemon wedge if desired.

ANALYSIS
Calories: 79
Carbohydrates: 0 g
Total Fat: 1.1 g
Protein: 15.8 g
Sodium: 58 mg
Potassium: 376 mg
Phosphorus: 201 mg
Successful grassroots advocacy efforts don’t just happen by accident, they require a LOT of people. Many people have become jaded about politics and decide to stay out of the process, but that is a problem. Everyone affected by kidney disease needs to lend their voice and share their experience! NKF needs advocates just like YOU! Here are a few common myths—and why they aren’t true.
MYTH I DON’T KNOW ANYTHING ABOUT POLITICS!
FACT You're the expert on your experience with kidney disease. You don’t need to be an expert on the political process to have a huge impact on policy. Your elected officials want to hear your personal story. 97% of staffers on Capitol Hill feel that a visit by a constituent (person who lives in their district) has a significant influence on a legislator’s decisions. Practice telling your story—try different versions, both long and short. In case you are pressed for time, you can still make your story powerful.

You are never alone in the fight.

MYTH I WON’T MAKE A DIFFERENCE.
FACT Everybody's story is unique. Members of Congress are often influenced by stories from their constituents. Advocacy is about many people who care about kidney disease issues sharing their stories. When we all come together we have the power to affect change. If everyone thought “I don’t matter,” then nothing would ever change! Luckily, NKF has a built-in network of people who care about kidney disease just like you—so you are never alone in the fight.

MYTH NOTHING EVER HAPPENS IN DC.
FACT While some would argue that Congress has been less productive over the last decade, many bills are still passing. Advocacy is also about laying the groundwork for future years, and is not just about making a big splash. Most bills take several years to mature, and sometimes it is important to advocate to prevent harmful legislation from passing Congress.

MYTH ADVOCACY IS HARD AND TAKES TOO MUCH TIME.
FACT There are many ways to participate and have a huge impact. While meeting your legislator in person requires time, you can call their office or write a letter about NKF priorities. You can tweet or post on Facebook about important bills or issues and share it with them. All of these things add up to make a big impact and do not require a lot of your time.

MYTH LEGISLATORS DON’T CARE ABOUT THE OPINIONS OF PEOPLE OF THE OTHER PARTY!
FACT They may not always vote the way you would like them to, or support all the issues you support, but legislators care about the lives and views of their constituents. More importantly, many issues such as preventing and managing kidney disease go beyond “politics.” Don't hesitate to reach out to your local rep because of a difference in political views—it's even more reason why they need to hear from you!

KIDNEY ADVOCACY VICTORIES IN 2016

Advocating relentlessly on behalf of kidney patients, the NKF is proud of the accomplishments we have recently achieved that affect dialysis patients:

21ST CENTURY CURES ACT
Last December, the President signed into law the 21st Century Cures Act (H.R. 34). This law allows dialysis patients the option to enroll in Medicare Advantage (MA) plans. Patients will be able to access these plans in 2021. The delay allows time for MA plans to make changes to better meet the needs of patients with kidney failure. Additionally, the 21st Century Cures Act will enable patient self-management of chronic disease(s) through telehealth and health information technologies, and works to address racial health disparities. It will also invest $4.8 billion in the National Institutes of Health (NIH) for research on chronic diseases.

NEW FDA KIDNEY-FRIENDLY FOOD LABELING
Last May, the FDA announced its final changes to the Nutrition Facts Label found on packaged foods. The new labeling requires food manufacturers to list the amounts of potassium and calcium on the nutrition label beginning July 28, 2018. This is an especially great win for kidney patients who often find it challenging to know how much potassium and calcium are in the foods they buy.

IMPROVEMENTS IN THE MEDICARE DIALYSIS FACILITY STAR RATINGS PROGRAM
NKF was successful in working with the Centers for Medicare & Medicaid Services (CMS) to change its Dialysis Facility Compare Star Ratings Program to make it more in line with how kidney patients want to get information about the quality of care provided in dialysis facilities. Patients report that they prefer to see star ratings assigned based on how well the facility delivered care rather than having stars assigned to facilities based on a curve—like high school students whose test scores are based on how well they did in comparison to their peers. The new way CMS will assign star ratings better ensures that facilities will still receive a star rating in line with the standard of care they provide.

Thelma Barber, SC

Our success would not be possible without YOU! Join our Take Action Network today!

kidney.org/advocacy
Feeling Fit and Fabulous

Spring is around the corner and it’s a perfect time to start exercising!

We have all heard that exercising is good for our overall health, but do you know why? Exercising can improve heart health, decrease blood pressure, improve blood sugar control, improve bone density, prevent obesity, and even decrease your risk of death. In addition, it’s a great stress reliever and can help fight depression. For people on dialysis, heart disease is the #1 leading cause of death so exercising can be a great way to combat any issues.

You might think that exercising is too much for you. If you don’t want to bulk up, run a marathon, or even jog - that’s okay! There are many different ways to exercise and most are good for you and your heart. Talk with your healthcare provider about any limitations you may have. Then, start at your level and work up! A good place to start for someone who has not exercised in a while is with short (10 min) exercises - this can be walking, cycling, or even jumping jacks in place at your home.

You can even exercise while sitting in a chair or using exercise bands. The most important part is to make exercise a part of your regular routine and stick to it! Another must have: good shoes!

For many older adults, building muscle mass is an important part of exercise in addition to heart health. Maintaining muscle mass will help you stay independent and able to complete your daily activities.

How will I know if I’m exercising “right” or “enough”? You should start slow and warm up your body before doing anything more high impact. Also, allow yourself time to cool down and stretch after working out. You should feel breathless and fatigued, and if you do higher impact exercise you should sweat too. If you have any pain, stop exercising right away. Seek medical help if you have sudden chest pain. If you feel dizzy, faint, or can’t catch your breath, sit down right away. If possible, find an exercise buddy.

To start, you only need 10 MINUTES!

Get started today!
Talk with your healthcare provider before starting any exercise program. If you are weak, you may qualify to see a physical therapist. Also ask about the possibility of exercising from your dialysis chair with a foot bike or exercise bands. Stay motivated and improve your quality of life!
WHAT KEEPS YOUR SPIRITS UP?

HOW DOES HUMOR HELP YOU?

Studies have shown that belly laughs can produce the same cardiovascular benefits as rigorous exercising. Humor improves your mind, accelerates healing, lowers anxiety, and slows the aging process. I am one of thousands of people on dialysis in this country. So, for me laughing is essential. When someone asks me, “How do like dialysis?,” a quote from Maurice Chevalier comes to mind. When someone asked him how he likes being in his 80s he replied, “Considering the alternative, I like it”! I like to concentrate not on my DISABILITY, but rather my ABILITY. I like to keep my dialysis friends’ spirits up also. I do this by hosting dinner parties at my home, so we can laugh, eat, and stay merry. –Lela C. Zappetti

Taking 20 to 30 minutes to meditate a day and step away from the drama of life always makes me feel renewed and refreshed. –R. Nelson

I try to eat a healthy diet and I like to do a lot of walking. I love to help people. –S. Scott

I find myself to be really funny. I am always making myself laugh so that definitely keeps my spirits up. It’s an added bonus if others find me funny, too. If not, I still get a good chuckle out of most things that come out of my mouth. I am also an avid Ellen DeGeneres fan. I watch her show every day. –A. Leonard

I have been writing about music for a wide variety of publications for 35 years, so music is my salvation. I enjoy reviewing new CDs. I have music on while I clean the house and wear headphones every night just before I hook up to the PD cycler. –M. Gallo

Being kind to others keeps my spirits up. One little “hi” or “can I help you” goes far in someone’s day and in my own. Kind, courteous, helpful, and understanding of others will always uplift others and yourself. Being kind to one another should be practiced more often. –C. V.

I like to wear headbands, hats or simple costumes to commemorate the holiday (be it the first day of spring, Easter, Flag Day, or whatever). It never fails to bring a smile. I’ve become known for it in my community, and people are disappointed if show up without it. –J. Carter

Laughing relaxes my muscles and mind. I forget about any bad feeling or pain. I think stress is an issue for people with kidney disease. I watch funny cartoons or funny movies. I watch birds. I love when people are nice to me and to others. I wish I could laugh more. –Zulma

I am fortunate as I have a good team taking care of my dialysis sessions. They are very pleasant and fun to have. I keep up through prayer and keeping busy while I am having my treatment. Also, I have made friends with other patients and we lift each other up. All this works together to raise my spirits. –G. Woodcox

Family and interaction with others. Pets help as well. Also, reading a funny book or watching a comedy. The comradery one receives when going to work or volunteering also helps. –T. Sanders
Landmarks nation-wide went orange in support of World Kidney Day on March 9th.

Your FREE copy inside

kidney living®