

# Kidney *Chronicles*

END-STAGE RENAL DISEASE NETWORK OF NEW YORK

JUNE 2013

HELPFUL TIPS TO  
EMPOWER ESRD  
PATIENTS AS  
CONSUMERS



Improving Healthcare  
for the Common Good®

## Getting on the Transplant Wait-List And Coping with Pre-Transplant Stress

**A**s a patient with ESRD, it is important for you to consider all treatment options, including transplant. Talk to your healthcare team about your health and your treatment options. If you conclude that a kidney transplant is right for you, there are many steps to take before your name is listed on the United Network for Organ Sharing (UNOS) transplant waiting list:

- Follow the recommended treatment prescribed by your healthcare team (this includes following your dialysis treatment schedule and taking your medications).
- You may choose a transplant center (self-referral) or you can ask your physician for a referral. Make sure the transplant center meets your needs, e.g., financial, geographical, and type of transplant. Check the UNOS website ([www.unos.org](http://www.unos.org)) or call the IPRO ESRD Network for information on the transplant programs available across the country.
- Transplant centers have varying requirements. You may need to have further tests/workups prior to being placed on the waiting list (such as cardiac, pulmonary, dental, etc). Ask the transplant coordinator about the tests/workups required to get on the wait-list.
- Schedule an appointment with the transplant center of your choice.



### How the Network Serves You

- Advocates on your behalf;
- Answers your questions about treatment, modality choices or other issues;
- Develops and provides educational materials for you and your family;
- Works with renal professionals to improve the care provided to you;
- Helps keep you informed and updated to support your involvement in your care and treatment options; and
- Evaluates and resolves grievances.

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- Prior to the appointment, make a list of any questions you may have for the transplant team.

When it is determined that you are an appropriate transplant candidate, your transplant team will add you to the UNOS waiting list and notify you of your status. Do not assume that your name is on the waiting list; make sure you get a letter from your transplant center confirming that your name has been added to the list. If you do not hear back from your transplant team, follow up by calling your center's transplant coordinator.

Once you are on the waiting list:

- Make sure you keep contact information current with both the transplant center and your dialysis unit.
- Attend transplant unit follow up appointments.
- Ensure your dialysis unit draws and sends transplant monthly blood work to the transplant center.
- Pack an overnight bag when you are listed on the waiting list.
- Make sure you take care of your teeth. Dental health is important at all times, especially when waiting for a transplant.

## Coping with Pre-Transplant Stress

Waiting for a transplant can trigger feelings of stress and anxiety. To help manage stress, you can:

- Eat right, take your prescribed medications, and follow a daily exercise program approved by your physician.
- Share your feelings if you're anxious or uneasy. Your transplant team can answer questions and help alleviate fears. Your social worker can put you in touch with a support group.
- Spend time with family and friends. Good company will take your mind off waiting.
- Learn relaxation techniques, like reading and listening to music or relaxation tapes.

## Kidney-Friendly Cooking

With summer right around the corner, it is time to clean off the grill and cook out! Having kidney disease does not mean that you have to limit the number of picnics or activities that you attend. In fact, we encourage activity. Here are a few tips to help meet your healthy eating goals, (and grilling cravings):

- Eat more protein! (Chicken, fish, burgers, steaks, chops etc.)
- Stay away from added salt and foods high in sodium, such as chips, cheeses and processed foods like sausage, hot dogs, pickles and sauerkraut.

- Substitute store-bought marinades with a small amount of oil—or even better—make your own low-sodium marinade: Mix ½ cup olive oil, ½ cup balsamic or red wine vinegar, 1 tsp garlic powder, 2 tsp dried Italian seasoning. Great on chicken or fish! (makes 6–8 servings). Cook enough to save for leftovers.



- When you are making salads, add more protein (eggs, meat, etc.) and less lettuce.
- Bring a “kidney-friendly” side dish, like pasta or rice salad, and enjoy!
- Remember to look at the plate: half should be meat, eggs, fish, poultry and the other half should be everything else combined.
- Don't forget to take your phosphorus binders with you!

## To file a grievance, please contact:

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This material was prepared by IPRO End-Stage Renal Disease Network of New York, the ESRD Organization for New York State, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. CMS Contract Number: HHSM-500-2013-NW002C