

Heartland Headlines

A Newsletter for Kidney Patients



“Along with my faith and the support of my family, I can do all things.”

- Judy Robbins

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A Message from the PAC Chair....

Greetings,

My name is Judy Robbins and I am the new Patient Advisory Committee (PAC) Chair for Heartland Kidney Network. I have been involved with the PAC since 2008 representing the state of Nebraska. I began my journey with chronic renal failure when I was diagnosed in 1985.

I started on peritoneal dialysis (did that approximately two-three months), was on hemodialysis for ten years, received my first transplant which lasted for nine years, and now I am currently receiving in-center hemodialysis as I await for another kidney transplant.

I have been involved with the PAC because I am passionate about the mission. In 2017, the PAC is *organizing with patients, providers, community partners, Qsource, and Medicare to empower and educate*

renal patients and their families/ support systems by improving communication and resources to enhance the overall health, well-being, quality of life, and care of individuals with kidney disease. The Heartland Headlines patient newsletter is one of the ways we get information out to patients in Iowa, Kansas, Missouri and Nebraska. In this issue, you'll find stories about people living well with kidney disease and information about what you can do to live well too. I hope that you will find this newsletter helpful and will share it with others. I want all people living with kidney disease to feel like I do. That along with my faith and the support of my family, I can do all things. I have renal failure, it DOES NOT have me. Enjoy!

Sincerely,

Judy Robbins
PAC Chair

Patient to Patient: Sharing = Healing

*Kendra Deike
PAC Member from Iowa*

I used to think if I shared my story of dealing with ESRD it would hinder me because I fought too hard to be normal and fit in when I was young, trying to find my way. It wasn't until I was in my early twenties that

I realized God put me in this body for a purpose. By sharing my story it didn't just inspire others it also healed my emotional pain as well. I have been able to meet people who have gone through struggles and pain, we are able to relate and not feel so alone. We can accomplish so much by standing together and making an impact on the world. I have never given up or used kidney disease as a reason to not set goals and accomplish them in the process. I have always been supported by my family to reach for the stars and be a productive and strong woman. They did not give me permission to use excuses not to study and work hard.

I believe this has built me to go onto receive a Bachelor of Science in Business and Masters of Business Administration in Organizational Development from Upper Iowa University. I have a career with United States Postal Service and I am very proud to have the ability to have a job. The best advice that I can provide to others is to be



Kendra and her nephew, Preston

proactive when it comes to your health and you are the best advocate to what is going on with your body. It won't always be easy but you are the only one who can keep the communication open with your healthcare team. Keep accurate records and ask for copies of all your doctor notes and paperwork from each visit. Keep a folder of all your information and take it to each visit. Don't expect the medical staff to know more about your health than you do. And finally, don't be afraid to ask for help from your loved ones. I always wanted to prove to myself that I could handle it alone because my family had always done so much that I didn't want to be a burden on them. But they really do care and you need to keep them close. Thank you for letting me share my story. I wish you all the best.

Sincerely,

Kendra

Life Beyond the Chair ... Giving Back

There are many ways to share your time and talents with others. Whether its making a phone call to encourage a new patient, helping with a bulletin board, or attending a meeting to share your ideas, helping others is a great way to keep your mind and body active. If you are interested in helping other people living with kidney disease, Heartland Kidney Network has a program to help you work with a dialysis clinic to improve the dialysis experience for everyone. Contact the Network or talk with your clinic social worker for more information about the Network Patient Representative Program.



Barbara Briggs, The Stork's Nest in Omaha, Nebraska

Barbara Briggs, PAC Member and Network Patient Representative from Nebraska, shares her story of living "beyond the chair" by giving back to her community.

"Today, I was working the Stork's Nest, a community volunteer service operated by my sorority Zeta Phi Beta Inc., Beta Psi Zeta Chapter in Omaha, Nebraska. We operate through the University of Nebraska Medical Center (UNMC) with the help of our sponsor the March of Dimes as well as community donations. Our clients are pregnant mothers who get their services through UNMC. The store uses points instead of money. The mothers get points for such things as breastfeeding, keeping up the children's shots, continuing their education or bringing the dad to their appointments with them. They can then come to our store and use their points to "buy" a variety baby items from baby wipes to car seats. We are open the third Tuesday of every month in the daytime from 9:30 to noon and the evening from 5:30 to 7:30. I enjoy working the Storks Nest when I can, it allows me to serve others, and meet people from many other cultures."

"I enjoy working when I can, it allows me to serve others, and meet people..."



[My Network: NPR](#)

Cucumber Melon Salad

A kidney friendly diet can be hard sometimes, but you can still enjoy fresh and simple treats like this salad. Avery Wills, PAC Member, kidney transplant recipient and chef, recommends this sweet side for spring. This colorful salad is tangy and delicious. The unexpected combination is such a pleasant surprise. You can use whatever type of melon you have on hand.

Prep/Total Time: 15 minutes

Servings: 2

Ingredients

- 2 tablespoons canola oil
- 1 tablespoon lemon juice
- 1/2 teaspoon sugar
- Dash pepper
- 1 unpeeled small cucumber
- 1 cup cubed melon of your choice (watermelon is low in potassium, cantaloupe and honeydew are high in potassium)

Directions

1. In a small bowl, combine the oil, lemon juice, sugar and pepper. Cut a few slices from cucumber and set aside for garnish. Cut remaining cucumber into quarters, then cut into pieces.
2. In a serving bowl, combine cucumber and melon. Pour dressing over all; toss gently to coat. Garnish with reserved cucumber slices.

Nutritional Facts

1-1/2 cup: 92 calories, 7g fat (1g saturated fat), 0 cholesterol, 4mg sodium, 7g carbohydrate (0 sugars, 1g fiber), 1g protein. Diabetic Exchanges: 1-1/2 fat, 1 vegetable.

Originally published as Cucumber Melon Salad in Cooking for One or Two Cookbook 2003, p54



Cucumbers are a kidney-friendly option for many dialysis patients (always talk with your doctor or dietitian to make sure it's right for you). A 1/2 cup serving of sliced cucumbers is 90 mg of potassium. Potassium is a mineral found in many foods that you eat. Knowing the amount of potassium in your diet is important for people on dialysis because **if your potassium becomes too high, it can cause an irregular heartbeat or a heart attack.**

Monthly blood potassium levels are taken to make sure you are at a safe level. Ask your doctor or dietitian what your levels are.

For more information and a list of low and high potassium foods visit the National Kidney Foundation at www.kidney.org.



Cliff Robbins with his mother and two grandsons visiting the Lincoln Memorial in Washington, DC.

Throughout this issue you may notice a “magnifying glass symbol”. This symbol indicates that you can find more information about the topic in the MY KIDNEY KIT (at the dialysis clinic) or online by visiting www.mykidneykit.org.

The Freedom to Travel ... Just Do It!

- Cliff Robbins, Nebraska

This last Thanksgiving, I took my first trip as a peritoneal dialysis patient with my cyclor. I wanted to share some of the tips I learned along the way so all people living with dialysis can have the same freedom to travel.

1) Suitcase for cyclor. The staff at my dialysis clinic helped by lending me a special suitcase to carry my cyclor in with instructions on how to make arrangements with the airline to have it placed in the cargo hold.

2) Have supplies sent to the hotel.

Contact the hotel to let them know a shipment will be coming and ask who would be on duty to accept the supplies and store them securely until I arrived. Get the contact person’s name and number.

Then I contacted my supplier (Fresenius) to have my supplies sent to the hotel. They have a special division in the company that took care of it. They will need the a contact person from the hotel.

It is suggested that they arrive 1-2 days in advance of check-in. The supplier gave me a tracking number so I was notified when the supplies arrived.

3) Talk with airport security (TSA). I went to the airport two days before my trip to show them the suitcase and make sure I would have no problems. This is not required but it made me feel more comfortable that things would go smoothly.

4) The day of travel. ****It’s important that you have the cyclor stay with you until you board the plane**** The airline took the suitcase before I boarded and I could watch from the window as they loaded it in the cargo hold. It was a great relief to see it loaded and know it would make it with me.

Once I got to Washington, DC the travel became an afterthought and I was able to enjoy my trip visiting with four generations of my family. It was a very empowering experience... I will travel again because I know I can do it. Bon Voyage!



[MY LIFE: Traveling with Dialysis](#)



Weighing all your Options

Deciding which type of treatment is best for you isn't easy. Depending upon how you started dialysis, you may have had very little time to make a decision. Despite how you currently get dialysis you can look at all the options available. Your decision depends on your medical condition, lifestyle, and personal likes and dislikes. Talk to your health care team and family about the pros and cons of each option. The key is to learn as much as you can about the choices. Here are some of the pros and cons to think about.

In-Center Hemodialysis

Pros

- + Clinics are widely available.
- + You have trained professionals with you at all times.
- + You can get to know other patients.

Cons

- Treatments are scheduled by the clinic and are at set times.
- You must travel to the clinic for treatment.

Home Hemodialysis

Pros

- + You can do it at the times you choose- but you still must do it as often as your doctor orders.
- + You don't have to travel to a clinic three days a week.
- + You have more independence and control over your dialysis.
- + Newer machines require less space.

Cons

- You must have a helper.
- Helping with treatments may be stressful to your family.
- You and your helper need training.
- You need space for storing the machine and supplies at home.

Continuous Ambulatory Peritoneal Dialysis (CAPD)

Pros

- + You can do it alone.
- + You can do it at times you choose as long as you perform the required number of exchanges each day.
- + You can do it in many locations.
- + You don't need a machine.

Cons

- It can disrupt your daily schedule.
- It is a continuous treatment, and all exchanges must be performed 7 days a week.

Continuous Cycler-Assisted Peritoneal Dialysis (CCPD)

Pros

- + You can do it at night, mainly while you sleep.
- + You are free from exchanges during the day.

Cons

- You need a machine.
- Your movement at night is limited by your connection to the cycler.

Continued on page 7



[My Choices](#)

Weighing all your Options

Continued from page 6

Kidney Transplantation

Pros

- + A transplanted kidney works like a normal kidney.
- + You may feel healthier or “more normal”.
- + You have fewer diet restrictions.
- + You won’t need dialysis.
- + Patients who successfully go through the selection process have a higher chance of living a longer life.

Cons

- It requires major surgery.
- You may need to wait for a donor.
- Your body may reject the new kidney.
- You will need to take immune-suppressant medications for the life of the kidney, which may cause complications and side effects.

Visit www.mydialysischoice.org for a helpful tool to help you decide.

Transplant 101: Types of Kidney Donors*

Living Donor

- A living related donor kidney comes from a blood relative, such as a parent, brother, sister, or an adult child, and is the best transplant option.
- A living unrelated donor kidney comes from someone who is not related to the person receiving the kidney.
- The donor is evaluated by the transplant center to make sure he/she is healthy enough to donate and is offering his/her kidney willingly, without pressure from anyone.

Non-Living Donor

- A non-living donor is someone who has recently died and has donated a healthy kidney.
- Patients who do not have a living donor can be placed on the national organ transplant waiting list to receive a deceased donor kidney.

Kidney Donor Exchange

- If your kidney donor is approved for a living donation but is not a match with you, you and the donor may be able to join a living donor exchange program.



Help for People Helping with Living Donations

The National Living Donor Assistance Center offers a program to help people who want to become living donors. For some people, the money needed to cover non-medical expenses (not covered by insurance) may prevent them from becoming a donor. In order to help with this barrier to transplant, the NLDAC program offers help with the costs of hotel, travel and meal expenses to people who qualify. Call 1-888-870-5002 or visit their website for more information about how to apply and qualify for assistance. Your transplant program will need to help file an application on your behalf to the NLDAC. www.livingdonorassistance.org.

Tell us what you think of this newsletter. Your feedback is important to us! Visit https://www.surveymonkey.com/r/HKN_HH to share your thoughts.

For more information, to request a printed copy of this newsletter or to file a grievance please contact :

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Qsource
ESRD Network Strategies



With the rain comes the flowers... Cause & Effect

There's a lot to learn and do when you are living with kidney disease and need dialysis.

Sometimes it is hard to keep track of everything and do everything "right". But knowing the possible side-effects that can come from not following the "rules" can help you make better choices.

Too much fluid being removed during dialysis

May cause → Low blood pressure, nausea and dizziness and/or muscle cramps.

- ✓ Talk to your doctor about when to take any medications for high blood pressure to make sure you time it right.
- ✓ Limit the amount of fluid you drink between treatments.

Too much phosphorus

May cause → itchy and/or dry skin

- ✓ Take your phosphate binders with food.
- ✓ Follow your diet guidelines from you dietitian.
- ✓ Avoid hot showers and harsh soaps, use lotions and creams without alcohol in them.

Medicare.gov | Dialysis Facility Compare

The Official U.S. Government Site for Medicare

[Dialysis Facility Compare Home](#)
[About Dialysis Facility Compare](#)
[About the Data](#)
[Resources](#)
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Home Share

Find a dialysis facility

A field with an asterisk (*) is required.

* Location
Example: 45802 or Lima, OH or Ohio

ZIP Code or City, State or State

Dialysis Facility Name (optional)
Full or Partial Dialysis Facility Name



Check out Dialysis Facility Compare to look for dialysis clinics where you plan to travel or to compare clinics in your area. Find clinics and compare their services by going to: www.medicare.gov/dialysisfacilitycompare/

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