

Heartland Headlines

A Newsletter for Kidney Patients



PATIENT TO PATIENT

Meet Cary Higgins: My Dialysis Story

Cary Higgins' story about how his life was changed by advanced kidney disease is, like many, a complicated tale. Only after two month-long hospitalizations did he and his family receive the diagnosis. He was discharged from the first of these hospitalizations with a diagnosis of Lou Gehrig's disease (or ALS). A month later, he was re-admitted following a mild heart attack. Multiple tests were performed and the ALS diagnosis was replaced by scleroderma, a rare disease that is capable of shutting down a person's kidneys. For Cary Higgins, the disease had indeed impacted his kidneys and to a significant degree. Dialysis treatments were started and have continued for the past five years. He notes, "Treatment at dialysis has had its ups and downs... mostly uneventful." His biggest concerns are cramping and fatigue. However due to changes in Cary's fluid intake as well as modifications to his treatment plan, the cramping is "pretty much in the past now."

Cary wants all patients to know: "Tough question. There are many things I think patients can DO. There are many things I think they SHOULD do. They will all discover those things by themselves over time. Some will choose to do those things; others will choose to live their lives unchanged and take their chances. I, myself, have played it both ways over the past five years. By doing that, I would have to be an idiot not to have learned a few things. So I won't offer up things they can do or should do. Instead I'll tell them what they should KNOW. And that is simply....you can play it your way for only so long. If you refuse to follow several rules, you'll die sooner than need be. That's the harsh reality of it – an earlier death. Think about that very seriously and make your choice. I've discovered that kidney failure, odd though it may seem, is loaded with options that can benefit the patient which is unlike so many other diseases. Realize and know that so much is UP TO YOU."

Cary's proudest accomplishment: "I can honestly say that I don't recall ever having a goal in my life before six years ago. I accomplished a lot of stuff, but nothing that made me extremely proud. My attitude was "I'm able to do this, so I'll do it". The FIRST real accomplishment I can feel proud of was while I was a dialysis patient. I pushed my wheelchair up Brady Street in Davenport, Iowa during the Quick Bix 5k walk/run. I had to sit down halfway up the hill. The electronic finish line was all packed up by the time me and my two therapist friends crossed it. BUT I DID IT!!! So basically, my proudest life accomplishment is....I HAVEN'T GIVEN UP. EVER."

Mr. Higgins is the Network Patient Representative (NPR) for Mercy Renal Dialysis Clinic in Clinton, Iowa. NPRs are individuals that are on dialysis or have had a kidney transplant who volunteer at their dialysis clinic working with staff to help improve the patient experience through education and fun.



[My Network - NPR](#)

All individuals in this newsletter have provided consent to release their name and images.



"I HAVEN'T GIVEN UP. EVER."

-Cary Higgins

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Patients considering home dialysis have questions about Medicare-covered services and supplies. The following is one question recently received by Heartland Kidney Network: *“Can I receive a reclining chair to use with my home hemodialysis therapy?”*

Answer: *Effective January 1, 2011, the dialysis clinic is responsible for fulfilling the requirements necessary for furnishing home dialysis. Coverage of any item of equipment used for home dialysis depends on its medical necessity and an order from a physician.*

Fulfilling the requirements for furnishing home dialysis should also be discussed in a care conference with the patient and the rest of the team, and should be added to the patient’s Plan of Care.

Home dialysis equipment includes, but is not limited to: Adjustable chairs, such as recliners.

These chairs serve to preserve patients’ health by allowing for quick changes in body

position when medically needed during dialysis (e.g., when acute hypotension occurs and the patient is in danger of going into shock).

If you have a specific question about Medicare-covered services or supplies, you can ask your care team or call the Heartland Kidney Network office at 1-800-444-9965.

Your feedback is important to us!
Please visit or click the link:
https://www.surveymonkey.com/r/HKN_HH
to tell us what you think about this newsletter.

The MY KIDNEY KIT Resource Symbol



Throughout this issue you may notice a “magnifying glass symbol” at the end of certain articles. This symbol indicates that you can find more information about the topic located in the MY KIDNEY KIT at your clinic. OR, if you are viewing this online, just click on the words to go directly to the page.

Values Matter

Every patient has the right to know about the treatment choices available: in-center hemodialysis, home hemodialysis, peritoneal dialysis and transplant. Recognizing your values related to lifestyle, health and family can help you when you are looking at the different treatment choices you have to live with kidney disease. Medical Education Institute developed My Life, My Dialysis Choice as a tool to rate your values and to help you decide what treatment choice would be best for you. Visit <http://mydialysischoice.org/> to use the online tool.



[My Choices](#)

TAKE CONTROL OF YOUR THIRST

► Pass on the salt

- Cook with herbs and spices instead of salt
- Try: Allspice, Basil, Bay Leaf, Caraway, Cardamom, Curry, Dill, Ginger, Marjoram, Rosemary, Thyme, Sage, Tarragon
- Avoid salt substitutes and foods made with salt substitutes- they are high in potassium
- Read food labels and choose low-sodium options

"I find it easy to eat applesauce and crushed ice to quench my thirst."

-Barbara Briggs, Nebraska

► Spray your mouth

- Try mint or lemon flavored water

► Brush your teeth

► Keep your mind busy

- Read a book
- Do a crossword or word-search puzzle
- Try crocheting or sewing

► Stay cool

- Stay in the shade or indoors
- Stay on the lowest floor out of the sunshine if air conditioning is not available
- Dress in loose-fitting, light-weight and light-colored clothes
- Wear a hat

*****Limiting your fluid will help you feel better and stay healthy before, during and after dialysis with no cramping or blood pressure changes during dialysis.*****

► Suck on ice chips

► Sip don't gulp

► Limit caffeine and alcohol



EXPLORE YOUR FUTURE TODAY

AAKP 42nd National Patient Meeting | Nashville, TN | September 23-25, 2016

The 2016 American Association of Kidney Patients National Patient meeting will be September 23-25, 2016 in Nashville, TN. For information visit www.aakp.org/community.html or call 1-800-749-2257. Scholarships are available!

5 Ways to Protect Your Vision

1. Get regular eye exams.
2. Eat a healthy diet and maintain a healthy weight.
3. Know your family's eye health history.
4. Wear sunglasses that block out 99% to 100% of UV-A and UV-B radiation (the sun's rays).
5. Quit smoking or don't start.

For more information visit <http://www.cdc.gov/Features/HealthyVision/>

Your Rights & Responsibilities

You have the right to choice.

- You have the right to choose your own doctor.
- You have the right to choose the dialysis clinic you want to go to.
- You have the right to be educated about the various types of treatment, such as in-center hemodialysis, home hemodialysis, peritoneal dialysis, and transplant.
*Not everyone is a candidate for every treatment method, but those who are not suitable have the right to be told by their doctor why they are not.
- You have the right to make your treatment choices in partnership with your own kidney doctor.

You have the responsibility to:

- Treat other patients and staff in a fair and polite manner.
- Be involved in making your treatment plan and follow it.
- Follow the rules and policies of the clinic.
- Tell your care team if you do not understand your medical condition or treatment plan.
- Be on time for your treatments. Call if you know that you are going to be late or miss a treatment.
- Let staff know if your insurance changes. You are responsible for the payment the dialysis services.



[My Network - Rights and Responsibilities](#)

Life Beyond the Chair

Living with kidney disease and being on dialysis requires lifestyle changes and adjustments but you can still live an active and meaningful life. Here's how a few of our Patient Advisory Committee members are living "life beyond the chair."



What a catch! Mike Ashley from Iowa.

Carmen Reinke from Kansas, walking the red carpet and celebrating at the Kansas City Royals Fan Fest in 2015.





Speak Up and Share Your Concerns

You have a right to file a grievance.

No topic is too small. **SHARE** any concerns.

When you file a grievance, you have the right to be **ANONYMOUS**.

YOU are part of your health care team.

You should **FEEL SAFE** when you file a grievance.

Contact the Network if you feel intimidated after you voice your grievance.

You can file a grievance at **ANY TIME**.

You have the right to file a grievance with the:

- Clinic
- Heartland Kidney Network
- State Survey Agency

You can file a grievance with the Network or State Survey Agency at any time and do not have to go through the clinic process first.



[My Network- Grievances](#)

How do I file a grievance with the Network?

You can contact the Network by phone, mail or email. The Network has an experienced staff available Monday through Friday. Call toll free at 800-444-9965 or email net12@nw12.esrd.net.

The Network acts as a neutral third party to help mediate concerns. We will listen to both sides and try to assist you to reach the best possible outcome for everyone. Depending on the details of your concern, the Network may take several roles including a referral source, case coordinator, facilitator, expert investigator, and/or advocate. Network staff may offer several options when you call including:

- **Confidential Consultation** – you just want to talk with someone about your care or want information and resources.
- **Immediate Advocacy** – you want the Network to help you and the clinic find a solution for your concerns.

- **Quality of Care Review** – you want the Network to review the medical care given to you or others by the clinic.
- **Referral** – your concerns fall under the responsibility of another agency and you will be provided with the contact information for the other agency.

In addition to helping with grievances the Network also works with clinics to improve patient care and satisfaction. This includes quality improvement projects, patient and clinic staff education and working with clinics to ensure patients have access to the dialysis care they need.



-by Jeff Walser, Patient Travel Pro

Many people on dialysis think that since they are on dialysis they can't travel anymore, but you can, it just takes some planning. Several steps are important to take before you leave on your trip so you can enjoy it. Travel to other locations in the United States is not hard... after trying it the first time, it will not be as difficult as you might have imagined.

1. Give the clinic you want to visit plenty of time. One month before your trip will you have the best chance of being accepted. Most clinics will allow less lead time, but they are always happier with more.
2. Find the travel contact person in your clinic. Do not contact your destination clinic yourself. In many clinics the social worker coordinates patient travel or the social worker can direct you to the right person to help you.
3. Give your travel contact person information such as:
 - The dates that you will be out of town
 - The number of treatments you will need while away. Work with your nurse to determine how many treatments you will need.
 - Possible locations of clinics that you might use in the city you are visiting.

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

Heartland Kidney Network
920 Main Street, Suite 801
Kansas City, MO 64105
Toll-free: 800-444-9965

net12@nw12.esrd.net or heartlandkidney.org

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Jeff Walser is the Medical Review Board Patient Representative for Iowa and serves on the Patient Advisory Committee. He is also the NPR for his local clinic. During his 14 years as a hemodialysis patient Jeff has dialyzed at more than 20 clinics around the country.

If your travel contact person has experience in helping with travel, they may know how to use specialized websites to find hemodialysis clinics. Whenever I plan a trip, I find it more convenient to identify these clinics myself. Three useful websites are listed below.

1. The Nephron Information Center | Dialysis Units
<http://www.dialysisunits.com>
2. Dialysisfinder.com
<http://www.dialysisfinder.com>
or call 1-866-889-6019 to talk to a live dialysis placement specialist who can help especially when travelling to larger cities with many available choices.
3. Medicare.gov | Dialysis Facility Compare
<http://www.medicare.gov/DialysisFacilityCompare/search.html>



[My Life-Traveling with Dialysis](#)