

Heartland Headlines

A Newsletter for Kidney Patients

2017 Issue 2



*May every
Sunrise,
Bring you
Hope,
May every
Sunset,
Bring you
Peace.*

Unknown

Inside this Issue:

Patient to Patient	2
Dialysis Lifeline	3
Knock Out Needle Fear	3
W.O.W.– My Access	3
Medicare Part A, B or D?	4
Life Beyond the Chair	4
ICH CAHPS Survey	5
Quality Incentive Program	5
Talk Transplant	5
W.O.W.– Vocational Rehab	6
Ticket to Work	6
Speak Up	7
Disasters Don't Plan Ahead	7
Easy Snacks on the Go	8



Throughout this
issue you see a

“magnifying glass symbol”.

This symbol shows that you
can find more information
in the MY KIDNEY KIT (at
the dialysis clinic) or online
at www.mykidneykit.org.

On behalf of Heartland Kidney Network, the staff, Board of Directors (BOD), Medical Review Board (MRB) and Patient Advisory Committee (PAC) it is with great sadness and gratefulness that we honor the life of Judy Robbins in this issue of “Heartland Headlines”. In the last issue, Judy introduced herself as the new PAC chair. She had been working with the Network since 2008. Through the years, Judy advocated on behalf of patients.

Judy, encouraged other patients to be engaged and informed about their healthcare and shared her story and positive outlook to inspire others to live well with

kidney disease. She was also a huge advocate for organ donation. Judy always helped with feedback on the educational resources the Network develops to support patients. Before her unexpected passing, she had shared tips and ideas for this newsletter.

Judy will remain an inspiration to us all and we will dearly miss her beautiful smile, kind heart, positive outlook and passion for helping others.

In May of 2014, she wrote her story for the Network website. “Sometimes Life is a Bowl of Sour Lemons and Plums.” We would like to share it again in this issue’s Patient to Patient article.



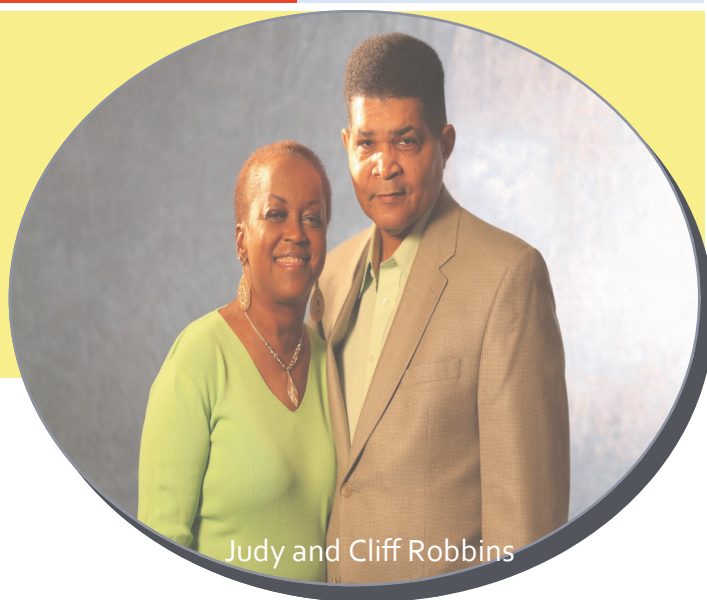
My Network:
Heartland Kidney Network

Patient to Patient:

"Sometimes Life is a Bowl of Sour Lemons and Plums"

By Judy Robbins

June 17, 1962– June 26, 2017



Judy and Cliff Robbins

Greetings,

My name is Judy Robbins. I'm a native of Nebraska, and will be celebrating 52 years of life on June 17, 2014. Life I must admit isn't always a bowl of strawberries and cherries. Sometimes it's sour lemons and plums.

In 1985, I started to experience some sour lemons and was diagnosed with chronic renal failure. I started on peritoneal dialysis (did that approximately three months) and endured hemodialysis for ten years. I then received my first transplant which lasted for nine years. Now I am currently receiving in center hemodialysis again on Mondays, Wednesdays, and Fridays as I await for another kidney transplant.

I don't care for sour lemons and plums, they leave a bad taste in your mouth. So I spend time with my family as much as possible. We enjoy going to the zoo, outside activities when weather permits, cooking, baking, and of course eating!! Sometimes we enjoy just sitting around laughing and talking. My wonderful husband of 25 years makes me feel special. He's always in my corner. He has turned the sour lemons and plums into sweet berries and cherries. Along with my faith and the support of my family, I can do all things. I have renal failure, it does not have me.

My good days outweigh my bad days so I won't complain. I continue to stay positive,

I have renal failure, it does not have me.

taking one day at a time, and I continue to become educated about what I'm experiencing. I always ask questions if I do not understand, even if I have asked them five times before. To me the end of the road is when you are no longer taking breaths; as long as you can breathe remember to breathe. Sometimes you may have to take deep breaths to get through the next moment or day. Just remember to be thankful you are breathing. Believe it or not there is always someone who is worse off than you are and having said that, I've turned my sour lemons and plums into sweet ones. It is true they are not sweet every day, but I take it as they come. This means that every Monday, Wednesday, and Friday is not "hi o cheery o!!" but I keep it moving by cherishing things that I love and love to do.

Dialysis Lifeline

You may have heard “your access is your lifeline”. This is the spot on your body where they connect the dialysis machine tubing to get “access” to your bloodstream for hemodialysis to occur. You may have a fistula, graft or catheter.

You need to talk with your doctor about the best type of access for you. Fistulas are the gold standard for hemodialysis. Grafts are the second best way and catheters are usually a temporary access. One of the biggest reasons catheters should not be used as your permanent access is because the tip of the catheter rests in your heart. If you get an infection it can be very serious or even fatal. Unfortunately, infections are more common with catheters than with fistulas or grafts.

Taking care of your lifeline is important for all dialysis patients. Getting a fistula or graft is a great step to limit infections.



My Treatment: How do I stay infection free

My Choices: Fistula



My Choices: Self-cannulation

Words
Of
Wisdom



Shared by Dan Westcott, PAC Member from Kansas

When I started hemodialysis, I chose a fistula because I am young guy and my vascular system should be fairly strong and healthy. This was the longest lasting treatment option available and I figured it would mature quickly. Since I am a double amputee, I use my arms for everything and that did help grow a hearty fistula. Additionally, I had my surgeon place mine in the upper arm as opposed to the common forearm. The belief behind this idea was due to my wheelchair usage my forearms tend to get dirty from

the wheels. Changing the placement was all about keeping my access healthy and infection free. Other tips that I do to keep my fistula healthy is always washing my hands and never really touching it directly. If it feels itchy or odd I will run an alcohol pad over it. This works as a way of cleaning it and agitating the skin enough to satisfy the itch. The greatest tip I can offer for keeping ones fistula healthy is exercise. Working out the body is great for tons of reasons but it will help produce a thriving fistula.

Knock Out Needle Fear!

Many people may not want to get a fistula or graft because of fear of needles. Asking questions is one of the first steps you can take to beat any fears you may have. Here are a few to get

Pain. I am worried about pain from the needles.

- Ask about using a pain killing cream or gel to numb the spot before they stick the needle in.

Fear. I am afraid of needles.

- Ask the social worker and doctor for ideas about ways to relax. There are also medications that may help.

Control. I want to be in control of my care.

- Ask about training to put the needles in yourself. Knowledge fights fear because you have more control.



Medicare Part A, B or D?

When it comes to Medicare there are lots of letters to figure out. The different “parts” cover different kinds of healthcare. In general, they cover the following:

Part A – Hospital costs

Part B – Outpatient health care costs

Part D – Medication costs

There are many different Part D plans so you need to pick the one that will work best for you. Visit www.medicare.gov to find and compare different plans. You can also call your State Health Insurance Program.

Iowa: 800-351-4664

Kansas: 800-860-5260

Missouri: 800-390-3330

Nebraska: 800-234-7119



My Network:
Medicare Part D

Life Beyond the Chair: *Living life to the fullest!* *Shared by Ardy Boucher, PAC Member from Iowa*



Ardy and Jim Boucher and Family, 2017

I am active in my church and have had the privilege of working with the Heartland Kidney Network serving on the Board of Directors, Medical Review Board, chairing the Patient Advisory Committee (PAC) for eight years. I am still active on the PAC with many wonderful people who are committed to bringing knowledge and

encouragement to dialysis and transplant patients in our four state area. I also serve on the National Kidney Foundation on the golf and walk

committees. Without dialysis to sustain me, I would not be able to be this active. I love life and enjoy every moment I can.

This year, my husband and I went to Disney World with our grandson, his wife, and our two great grandsons. WOW what a great time we had! Do I have bad days like everyone? Yes, I do. But, I think how blessed I am and know that with God in my life I can overcome all things. You can live a full and productive life on dialysis by keeping a positive attitude, keeping relationships with friends, keeping faith, prayer, and remembering "Life is a Gift" and we should embrace it, love it, and live it to the fullest.

Ardy has been living with kidney disease since 1971, has had two kidney transplants, is currently on hemodialysis, and plans to return to home hemodialysis.



My Network: **PAC**

ICH CAHPS Survey

Have you ever seen or heard of this before?

ICH CAHPS (said like “I.C.H. caps”) Survey stands for the In- Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems Survey. The ICH CAHPS Survey asks adults with kidney disease about their patient experiences with care from their dialysis facility.



How do I take the survey?

A survey vendor (not your dialysis facility) approved by Medicare would contact you by phone or by mailing you a paper copy.

Why is it important to take the survey?

If you are randomly picked for the survey, it is your chance to share about your dialysis experience and make it count. All your answers are kept private and are never linked back to your name. The overall facility results are used in a few ways:

1. Dialysis staff use the results to measure the quality of their patients' experiences and look for ways to do better.
2. Medicare uses the results to check facility performance.
3. Results are online so you can compare facilities.

QUALITY INCENTIVE PROGRAM

Medicare made the Quality Incentive Program (QIP) to improve dialysis patient care by setting performance standards for quality of care. This includes the results from the ICH CAHPS survey. Clinics who do not meet the performance standards may get a payment reduction of up to 2%. Each year the clinic will put up a new Performance Score Certificate for you to see how they are doing.



[My Network: QIP](#)



*Shared by Mike Bronson,
PAC Member from Kansas*

It is incredibly hard to be on dialysis. You don't feel well. Your diet is very restrictive. You are cold most of the time, if not all of the time. You don't want to go to the clinic. When you are waitlisted, it seems as if you will never receive a transplant. It is very easy to lose hope.

I never dreamed there would be a day when God would allow me to do everything I could do before a transplant. This picture of my wife and me was taken after a 4-mile hike up the side of a Colorado mountain. Do everything you can to stay healthy. **Your day will come!**



Mike and Tara Bronson

Words
Of
Wisdom

Shared by Judy
Robbins

In 1986, I took advantage of Vocational Rehabilitation training in my area. I did so, because I didn't want dialysis to **be my life** just **part of it**. I found out I was real good at data entry and ended up getting a part-time job. I guess my point is, if you can take advantage of what Vocational Rehabilitation has to offer – do it. It's a way to meet new people and find out your strengths.

Vocational Rehabilitation (VR) is a federal-state program that helps people with physical or mental disabilities get or keep a job. To find your local VR office call:

Iowa: 800-532-1486

Kansas: 866-213-9079

Missouri: 877-222-8963

Nebraska: 877-637-3422



My Life: Occupation



What is the Ticket to Work Program?

- It is a **free** and **voluntary Social Security** program
- It offers **career development** for people age 18—64 who receive Social Security disability benefits (SSDI or SSI)
- It helps people return to work or work for the first time

Why choose to work?

- Earn more money
- Gain independence
- Meet new people
- Learn new skills

What are Work Incentives?

Work Incentives are special Social Security rules that allow you to:

- Receive training for new skills
- Improve the skills you already have
- Pursue your education
- Try different jobs
- Start a career
- Gain confidence

For more information:

Call the Ticket to Work Help Line at 866-968-7842 or 866-833-2967 (TTY), visit www.socialsecurity.gov/work, watch Ticket to Work Videos at <http://www.youtube.com/choosework>. They also offer monthly WISE webinars to learn more about your rights and the resources available.

Speak Up!

The Network is here to help you if you ever have a concern about your clinic that you need to talk about or you want looked into. You can always contact us and do not have to go through the clinic's grievance process first and you have the right to be anonymous. The Network also helps to make sure everyone who needs dialysis has access to the care they need.

Call the Network with your questions or concerns at:

800-444-9965.



[My Network: Grievance](#)

What will happen if I call the Network?



Network staff will listen to you, ask and answer questions and talk with you about what can be done to help you with your concern.



With your permission, the Network may then start calls with the clinic to talk and work with you all to help with your concern.



The Network may review your medical record to learn more about the care you were given.



The Network may send your grievance to another agency if they have the authority over issues like your concern.

Disasters Don't Plan Ahead. You Can.

An emergency or a disaster can occur at any time. Floods, ice storms, heat waves, tornadoes, loss of electricity, and many other events could get in the way of your dialysis. As a kidney patient you need to know ahead of time what you can do to stay healthy

during an emergency. Having an emergency kit and plan can help you be prepared. For more information visit www.ready.gov. Here are a few things to do to get you started:

- Ask your clinic who to call if you can not get in for treatment.
- Give your clinic more than one emergency number they can call if the clinic has to close.
- Talk with the dietitian about an emergency diet.
- Check out the My Kidney Kit "My Plan" section on emergency planning.

Words
Of
Wisdom

Shared by
Judy Robbins.

I have found that it helps if I set my medications in a weekly pill holder. Whenever my medication bottles get low I start the re-order process. Another way that helps me is the automatic refill program through my pharmacy, they text me when it is time for a refill and ask me if I need that medication.



[My Plan: Emergency](#)



2017

Disasters Don't Plan Ahead.
YOU CAN.



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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www.mykidneykit.org
www.facebook.com/heartland



Qsource.
ESRD Network Strategies



Adults need
vaccines, too!



VACCINES
are not just for kids.

My Life: Vaccines

This resource was (created, developed, compiled, etc.) while under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. Contract #HHS-500-2016-00012C. The contents presented do not necessarily reflect CMS policy.



Easy Snacks on the Go

Whether you are on a road trip or just doing errands around town, ideas for easy and renal diet friendly snacks can be a challenge. Here are a few ideas to consider:

High Protein Choices

- Hard boiled eggs (they sell them at some gas stations)
- Tuna snack packs

Crunchy Choices

*Aim for less than 100 mg of sodium per serving

- Unsalted pretzels
- Animal crackers
- Vanilla wafers
- Rice cakes

Fresh Choices

- Celery
- Baby carrots
- Apple slices
- Grapes

These ideas and many more were shared on a Dialysis Patient Citizen webinar by Jessianna Saville, RD. Visit www.dpcedcenter.org/june or her blog at www.kidneygrub.com for more information.