

Headlines

A Special Publication
for people with kidney disease.



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...and more stories just for you!



Tips to Be Prepared

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



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Social Media:

www.facebook.com/esrdnetwork12

Your feedback is important to us!

Visit **<http://bit.ly/2DjNTas>** to tell us what you think of this newsletter.

Throughout this issue, you will see a magnifying glass symbol.



When you see that symbol, you can find more information in the MY KIDNEY KIT (at the dialysis clinic) or online at **www.mykidneykit.org**.

NOTE: All individuals featured in this publication have given consent to release their name, image and information regarding discussed content.

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Honoring and Remembering our PAC Chair



On behalf of Qsource ESRD Network 12, the staff, Board of Directors (BOD), Medical Review Board (MRB) and Patient Advisory Council (PAC), it is with great sadness and gratitude that we honor the life of Mark Johnson in this issue of “Heartland Headlines”. In the 2019 Heartland Headline’s second edition, Mark introduced himself as the new PAC chair. Mark was a strong advocate for Network 12 and the end-stage renal disease (ESRD) Network Program. He passionately worked to improve the lives of all kidney patients at his dialysis clinic, in Iowa, in our Network region and the nation. His life is truly an example of how one person can make a difference in the lives of many.

Mark was diagnosed with end-stage renal disease in May 2009 and began dialysis that November. He started his treatment by doing in-center hemodialysis, then peritoneal dialysis, followed by home hemodialysis — with his mother, Charlene, as his caregiver — before returning to in-center. Mark ran a small restaurant in Iowa and traveled the country competing in chili cooking contests — becoming the 2007 World People’s Choice Chili Champion. He retired in 2012.



In 2016, Mark joined the Network Patient Advisory Council (PAC) representing Iowa, and soon began expanding his advocacy and leadership.

He later told us that becoming involved in the PAC changed his life by giving him an opportunity to share his experience and wisdom to help others. Mark started working as the Network Patient Representative (NPR) at DaVita-Atlantic, helping with patient education, providing support to other patients and more recently being part of their quality improvement team meetings.



Mark also represented Network 12 on the national level with the ESRD Network Coordinating Center. He participated in the Patient and Family Engagement Learning and Action Network, the Kidney Community Emergency Response Coalition Patient Learning and Action Network, and the Legacy Group. In 2019, Mark took on a leadership role at the Network and became PAC chair; began serving on the Network 12 Board of Directors; and represented Network 12 on the Forum of ESRD Networks' Kidney Patient Advisory Council.

Since becoming PAC chair, Mark helped to plan and presented at the “Living Well with Kidney Disease” patient meeting in Overland Park, Kan., presented at the Network Council meeting and the annual grievance webinar. His goal as PAC chair in 2020 was to help increase the number of Network Patient Representatives (NPR) in the region. He wanted each clinic in the Network to not only consider how having a patient engaged as a NPR could improve the overall patient experience, but also the life of the individual serving as the NPR, acknowledging their wisdom and giving them purpose.

Mark also gave of his time and talents volunteering with many national kidney organizations including the American Kidney Fund, the American Association of Kidney Patients, and Dialysis Patient Citizens. In addition, he served as a subject matter expert on several Technical Expert Panels for the Centers for Medicare & Medicaid Services (CMS). He was truly driven and committed to making the lives of people living with kidney disease better at all levels.

He was a kind and thoughtful leader, who listened to all viewpoints, shared his opinions respectfully, and had a great sense of humor. Mark wanted to make sure that all patients had a voice and was always willing to share his insight to help guide the Network's quality improvement projects and to create educational resources to support patients.

Mark will remain an inspiration to us all and we will dearly miss his sense of humor, steady leadership, kind heart and passion for helping others.





Patient to Patient

My Journey with Kidney Disease

“Weathering the Storm”

by Barbara Briggs



My journey with kidney disease has been a stormy one. You find yourself either in the middle of a storm, going through it or coming out of it. It hasn't been

easy. I was diagnosed with Lupus in 1980, followed by end-stage renal disease in the late 1990's.

I really didn't understand the cause and effect of the disease until it hit me like a hurricane. I was devastated. My life was good, I liked my job and had a good family environment. In the beginning, I was able to handle it and work until the storm stepped in and brought stress. Stress, I found out, was my worst enemy when trying to save a kidney. Eventually my kidney gave up in December 1998.

After I found out that I had to go on dialysis, mentally and physically I was not ready for this journey. In order to cope, I tried not to think about how stressful things around me were and focused on doing what the medical staff instructed me to do. Soon, I found myself making friends in the dialysis clinic. I watched other folks that were having a rough time and I became an advocate for the clinic. It was fun. I was being of some help to others and interacting with the staff on a professional level.

But hemodialysis made me very ill. I fainted and my blood pressure dropped low. Eventually,

my doctors tried peritoneal dialysis (PD) which worked much better. With PD, my mobility was great, because I was in a comfortable environment doing my own thing and able to travel and basically enjoy life again. I had to decide how I was going to handle this journey, because I was not expecting a transplant anytime soon.

The time I had to think while I did my home treatment prompted me to decide that I was not going to let this disease control me. I was going to be in charge if I was going to survive. Within two years, on March 11, 2002, I received my first transplant. For eight years I was happy. I went through Vocational Rehabilitation services and began working and basically doing my own thing again.

In January 2009, after 43 days in the hospital trying to save it, I lost my kidney. When you lose a kidney, you gain antibodies that makes it harder to find a match the second time around. I had to return to dialysis, this time doing in-center hemodialysis. I went into survival mode and asked God for patience and strength. Having a great support system and giving of my myself through volunteering helped to keep me going.

I was active in the local chapter of Zeta Phi Beta Sorority Inc., participating in community service activities like helping with the Storks Nest at the University of Nebraska Medical Center Women's Clinic and on the scholarship committee.



On Wednesdays, after dialysis, I enjoyed attending Bible study and just hanging out with friends. I also found it very comforting to volunteer at Educare Child Development Center on my off days.

Keeping busy, was for me, an easy way to not worry about when was I going to receive another kidney.

After waiting nine years, on May 10, 2017, I received a call at 3:30 in the morning. I thought someone was playing a joke on me. The nurse convinced me it was not a joke and gave me 10 minutes to think about it, because this would be a high-risk kidney. Exactly 10 minutes later, I decided to accept. I am so glad I did. I am happy and healthy, except when my arthritis kicks in. There are good days and bad days, but I always try to focus on the good and I thank God every day for walking this journey with me.

Barbara Briggs is a kidney transplant recipient from Omaha, Neb. Barbara has been a Network Patient Representative at her former dialysis center, DaVita-Omaha South, has served on the Network Medical Review Board as the Nebraska patient representative from 2017-2020 and has been on the Network 12 Patient Advisory Council since 2016.



Transplant Tools

Is a Kidney Transplant Right for Me?

This guide was created BY patients FOR patients considering a transplant.

This is the third toolkit developed and written by the Forum of ESRD Networks' Kidney Patient Advisory Council and is available to download free from the Forum website at

esrdnetworks.org/toolkits/patient-toolkits



My Transplant-Ready Workbook



In collaboration with the Missouri Kidney Collaborative, the Network developed the Transplant Workbook to walk patients and their care team through the transplant journey. Download at mokp.org/transplant/



My Network: ESRD Networks

Sharing Your Concerns Helping You and Others Too!

One reason people often give for not speaking up or filing a complaint is that they are worried the staff will treat them differently. Patient experts have shared they are concerned about their dialysis access being injured, staff ignoring and/or treating them poorly.

Don't be afraid. There are options for you to file your complaint (or grievance) anonymously (without sharing your name or identity) at your clinic, with the Network and/or with the State Survey Agency. Every patient has a right to file a complaint/grievance without fear of retaliation.

The Network takes these concerns very seriously. When there is a concern of retaliation, often the Network asks the clinic to do staff training to make sure all staff understand and act in a professional manner. The Network looks at each grievance as a chance to make things better for every patient.

We create resources to help inform dialysis and transplant staff and to improve the care given to patients throughout the region.

ESRD Network 12

Toll-Free: 1-800-444-9965

State Survey Agencies

Iowa: 1-877-686-0027

Kansas: 1-800-842-0078

Missouri: 1-800-392-0210

Nebraska: 1-402-471-0316



You Have the 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 a part of your healthcare team.
- You should **FEEL SAFE** when you file a grievance.
- **CONTACT** the Network if you feel intimidated before or after you voice your grievance.
- At **ANY TIME**, you can contact ESRD Network 12 to discuss your concerns and/or file a grievance, and you can also call the State Survey Agency for your state.



Tips for Addressing Concerns With the Clinic

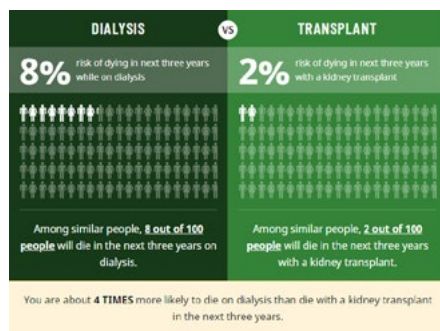
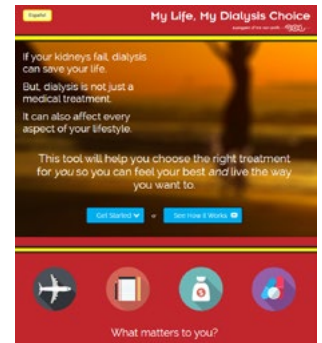
1. **Stay calm.** Stop, breathe and think about what your next steps may be before reacting. Sometimes we may say or do things when we are upset that we regret later. You may want to talk it over with a friend or family member.
2. **Talk** with a trusted staff member. Ask to talk with the social worker or clinic manager to discuss your concern.
3. **Ask** about the next steps. Each clinic must have a process with timeframes to follow up on your complaint.



Online Tools

Weighing Your Values and Risk

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. The Medical Education Institute developed My Life, My Dialysis Choice as a tool to rate your values and help you decide what treatment choice would be best for you. Visit mydialysischoice.org to use the online tool.



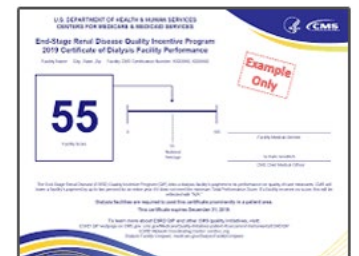
Emory University's iChoose Kidney risk calculator educates patients about the risk of available treatment options for kidney disease. This tool shows estimated risks of patient survival (probability of staying alive) and mortality (probability of dying) with different treatment options (dialysis or transplant) given the patient's demographic and clinical history at dialysis start. Visit ichoosekidney.emory.edu and enter your patient information to see how the options compare for you.

Have You Seen Your Dialysis Clinic's Score?

Medicare developed the Quality Incentive Program (QIP) to improve dialysis patient care by setting performance standards for the quality of care given to patients. Clinics not meeting the standards may have their Medicare payments reduced up to 2 percent. Each year the clinic will post a new "Performance Score Certificate" for you to see how they are doing.

You can also find and review dialysis facilities on Dialysis Facility Compare (DFC) at www.medicare.gov/dialysisfacilitycompare. Medicare looks at the patient health outcome data, including patient satisfaction survey data, to give each clinic a star rating. Each dialysis clinic gets a one to five star rating with three being the national average. A five star rating means a center is "much above average" when compared

to other dialysis clinics. A one or two star rating means the health outcomes for that clinic were below average.



Improving outcomes is a team effort. You can make a big difference by being involved in making your Plan of Care, following your diet, coming to every treatment and staying the entire time.

For helpful tips and information on the Dialysis Facility Compare website, check out the DFC Patient Education Handout available from the Forum of ESRD Networks in English or Spanish on their website at <https://esrdnetworks.org/education/dfc-education-resources>.

Tips to Be Prepared

Being prepared in case of an emergency or natural disaster is important for protecting your kidneys. Emergencies can happen at any time as severe weather often impacts our region. Here's how you can be prepared:



Mind Your Meds and Your Meals

- Keep a copy of your current list of medications and dosages with you
- Keep a copy of your dialysis orders (if you are on dialysis)
- Always keep a two-week supply of your medications on hand
- If you have diabetes, keep enough insulin and supplies on hand
- If you are on peritoneal dialysis, keep a five-day supply of the antibiotic your doctor orders for peritonitis
- Always keep a two-week supply of some foods with a long shelf-life
- Use a three-day emergency, dialysis friendly diet plan (3 Day Emergency Diets are available in the My Kidney Kit or available at www.kidney.org)



Check
expiration
dates
regularly.



Get Emergency Supplies in Order



My Plan: Three-Day Emergency Diet
(**Diabetic** | **Non-Diabetic** | **Pediatric**)

- For a full list of supplies, see [My Plan: In Case of Emergency](https://bit.ly/2I5noM9) (<https://bit.ly/2I5noM9>)
- Keep the basics on hand including flashlights, first-aid kits, distilled water, disinfecting wipes and cleaning supplies, masks, and extra batteries
- Battery-powered AM/FM radio to get emergency information if power and phone services are out
- Cell phone with chargers
- Food, at least a three-day supply of non-perishable food and a can opener
- If you dialyze at home:
 - Always keep a two-week stock of dialysis supplies
 - Register with your local water and power companies for priority restoration of services



Download a Patient Identification Card:

kcercoalition.com/en/patients/patient-identification-cards



My Plan: In Case of Emergency



Make an Emergency Plan

Consider and include the following:

- How will I get to dialysis if my regular transportation is not running?
- Where will I go if I must evacuate my home and/or my city?
- What will I need if I cannot leave home?
- What will I need if I must leave home?
- Who will I need to contact?
 - ☐ Include a list of important phone numbers for your doctors, dialysis clinic, support people and resources. Keep a printed copy in case you lose phone service. Include the name, address, and phone numbers for:
 - Dialysis Clinic: _____
 - Back up Dialysis Clinic: _____
 - Back up Transportation: _____
 - Kidney Doctor: _____
 - Pharmacy: _____
 - Utility Contacts: _____
 - Emergency Contact(s) in town and out-of-town: _____
 - Hotline numbers:
 - Dialysis Clinic Organization: _____
 - Kidney Community Emergency Response (KCER): 1-866-901-3773
 - ESRD Network 12: 1-800-444-9965
- ☐ For a list of dialysis clinics in the area, visit Dialysis Facility Compare at www.medicare.gov/dialysisfacilitycompare



My Network: Dialysis Facility Compare



Share Your Plan

Share your personal emergency plan with the dialysis clinic staff, family and friends. Make sure your clinic has the right contact information for you and your emergency contacts, including any out-of-state contacts.

Medicare Part D

Help to Find the Drug Plan That's Best for You

Medicare Part D is optional prescription drug coverage offered to those with Medicare. If you decided not to take Part D when you were first eligible, or you want to get it later, you will likely pay a late enrollment penalty. Each state has different Part D plans and covers different medications. You can add or change your Medicare Part D plan during the annual enrollment period. This year it is **Oct. 15 to Dec. 7**.

What will it cost?

Monthly Part D premiums vary according to plan and range from \$13.20 - \$89.60 in 2020. Depending on the plan you choose, there is also a yearly deductible. Once the deductible is met, each prescription will have a copay or coinsurance. Plans also include a gap in coverage often referred to as the “donut hole”, a time period in which medication costs will likely increase. The medications you take will determine which plan will be most cost-effective for you.

Find a Plan

Contact your state senior health insurance program (SHIP) to find out more about the plans available to you and/or to see if you qualify for extra help with the costs. You can also search for your options by using “Plan Finder” at: www.medicare.gov/find-a-plan/questions/home.aspx/.

Make sure to tell anyone helping you find a plan that you are a dialysis patient or have a kidney transplant. Have a copy of your medication list with you to compare the costs and plans. Each SHIP offers information and education on Medicare and free, unbiased, confidential, one-on-one counseling to help with decision-making and problem-solving.

State Health Insurance Programs:

Iowa: Iowa SHIP- Senior Medicare Patrol (SHIP-SMP) | 800-351-4664 | shiip.iowa.gov

Kansas: Senior Health Insurance Counseling for Kansas (SHICK) | 800-860-5260
kdads.ks.gov/commissions/commission-on-aging/medicare-programs/shick

Missouri: Community Leaders Assisting the Insured of Missouri (CLAIM)
800-390-3330 | www.missouricclaim.org

Missouri Kidney Program CLAIM counselors
800-733-7345 | umhsmokpinfo@health.missouriedu

Nebraska: Nebraska SHIP | 800-234-7119 | doi.nebraska.gov/ship



Getting Prescriptions in a Disaster or Emergency

Recent changes to the Medicare Drug Plan (Part D) affect how you receive medication during the COVID-19 pandemic. These changes include:

- Allowing you to get mail or home delivery in situations such as quarantine from retail pharmacies offering delivery services.
- Allowing you to get up to a 90-day supply in one fill unless quantities are more limited for safety reasons, thus relaxing their “refill-too-soon” policy.



If your state has issued a warning of a possible emergency or disaster, you should contact your Medicare drug plan if:

- You are not able to go to your usual network pharmacy to replace your prescription drugs. Contact your Medicare drug plan to find another network pharmacy nearby.

NOTE: A network pharmacy is a pharmacy that agrees to provide members of certain Medicare plans with services and supplies at a discounted price. In some Medicare plans, your prescriptions are only covered if you get them filled at network pharmacies.

- You had to leave your home without your drugs, or your drugs have been damaged or lost because of the emergency or disaster. They can help you find another network pharmacy.
- You cannot reasonably get to a network pharmacy; your plan can help you get drugs during an emergency or disaster at an out-of-network pharmacy. You may pay more for drugs you get at an out-of-network pharmacy. Save your receipts as you may qualify for a refund of your costs. Ask your plan for details.



Your plan’s contact information is on your membership card. Or search the plan’s contact information at www.medicare.gov/plan-compare or call 1-800-MEDICARE.



Debra Cohns
FKC - QCDC North
County in St. Louis

Ardyth M. Boucher Legacy Award

And the Winner is....

On behalf of the Qsource ESRD Network 12 staff, Patient Advisory Council and Boards, we would like to recognize Debra Gene Cohns as the 2020 winner of the Ardyth M. Boucher Legacy Award.

Cohns was nominated by staff at Fresenius Kidney Care at QCDC-North County in St. Louis. She has served for 18 years as an advocate for in-center dialysis patients. She goes above and beyond to support others at her clinic by checking in on those who have been hospitalized, bringing others food, going to the pharmacy and writing personal cards for holidays and birthdays. Additionally, she is an active member of her church and in her community and provides counseling to those in prison. “She continues to amaze the clinic with her compassion and generosity” - Kelsey Ricketts, MSW.

Cohns is an inspiration and great example of someone who balances life with dialysis while continuing to give of her time and talents with others. In her own words, we’d like to share Debra’s story.

“Hello, my name is Debra Gene Cohns, I am single, mother of one daughter, son-in-law and three grandsons. I am the eldest of five siblings — two which have passed. My brother died from lung cancer seven years ago, followed by a sister who died of congestive heart failure six years ago. I have two surviving sisters.

I currently reside in St. Louis. Born and raised here. I moved briefly to Dallas where I resided 22-months and returned because of the constant heat. I graduated from Forest Park Community College in Human Services. After graduation, I attended Harris Teacher-Stowe College. I taught in the St. Louis Public School system from 1975-1976.

The Ardyth M. Boucher Legacy Award was developed to recognize and celebrate a dialysis or transplant patient who is dedicated to patient advocacy and education to help improve the quality of life for kidney patients in Iowa, Kansas, Missouri and Nebraska.

The award is named in memory of Ardyth (Ardy) Boucher. Ardy was diagnosed with kidney disease at the age of 14. During her lifetime, she had three kidney transplants and did home and in-center hemodialysis. Ardy served the kidney community in many ways; generously sharing her time and talents with ESRD Network 12 on the Board of Directors, Medical Review Board and the Patient Advisory Council for more than 20 years.

In addition to working at a dialysis facility as a secretary for 27 years, she was active in her church and volunteered with the National Kidney Foundation. Ardy always encouraged other patients to be engaged and informed about their healthcare. She shared her positive outlook to inspire others to live well with kidney disease.

I worked for the St. Louis Police Department Headquarters for seven years and resigned in 1980 to become employed for the State of Missouri Family Services and after 26 years, I retired as a Child Support Supervisor I.

As an ordained minister, I have been an advocate and counselor for prisoners in 12 states. Since 1996, I have been sending cards and money. I sing and donate my singing at funerals. In 2018, I wrote and published a book entitled, “The Fiery Furnace”.

I love children and was a foster parent of eleven children from 1989-2001. I love the elderly and enjoy cooking meals for them. Before COVID-19, I visited nursing home residents and sick patients at hospitals.

I have been on dialysis since May 5, 2005 due to high blood pressure. In conclusion, I try at all cost(s) to exhibit a positive attitude. I try to be compliant and encourage others around me to do the same! Being on dialysis is very hard, but I advocate we are blessed to be alive. Good

doctors, nurse practitioners, qualified dietitians and technicians help us get the quality care we need and loving, caring family and friends have kept us alive.” — Debra Cohns

Debra's Tips for Other Patients

- Keep your dialysis access clean
- Watch phosphorus, protein, potassium levels
- Get adequate rest
- Try to attend dialysis regularly
- Make sure vascular appointments are scheduled regularly to keep access properly monitored
- Always report a change in home or cell phone numbers
- Report moving from home to nursing home or rehab facility
- Report new address if moved
- With the COVID-19 virus, I try to emphasize the importance of wearing a mask on nose and mouth, washing hands regularly, as well as using social distance practices whenever possible

Real People, Real Stories Podcast

One of the best ways to learn about how to live well with kidney disease is to hear from the experts-kidney patients. In keeping with the times, the Network has recorded podcasts with some of our Patient Advisory Council members. Real patients share their real stories about living with kidney disease on our Very Important Patient: Renal Review Podcast series. Visit esrdnetwork12.org/patients/patient-stories/ or scan the QR Code with your smartphone camera.



Mike Bronson
Kidney Transplant Recipient
Tonganoxie, Kan.

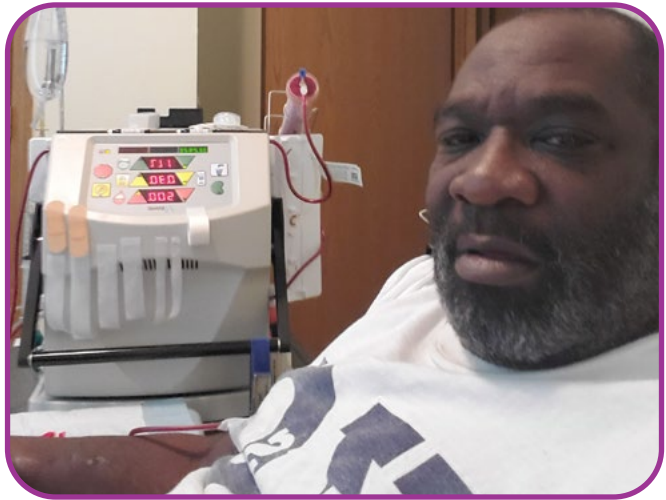


Anja Schlager
Kidney Transplant Recipient
Overland Park, Kan.

My Home Sweet Home

Many patients have shared that they do not think they could do home dialysis because of the size and/or set up of their home. We reached out to our Patient Advisory Council and Network Patient Representatives to find out what “home looks like to them” by sharing pictures of their home set up. Special Thanks to Dawn and Jimmy Bates, Michael Beteet, Jeffrey Cauley, Rosie Lindsey and Sherry McCormick for giving us a peek into their dialysis set up at home.

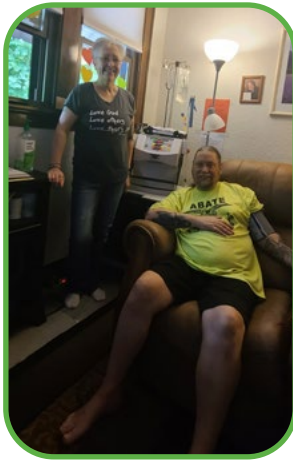
Jeffrey's Home Hemodialysis Setup



Michael's Home Hemodialysis Setup



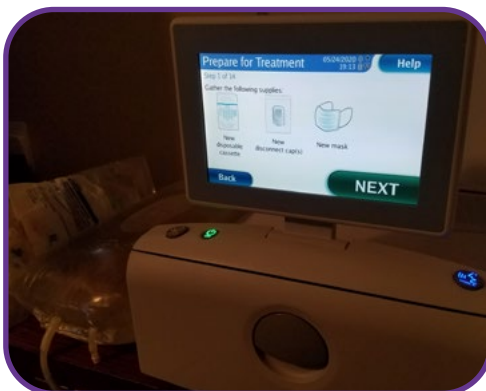
Jimmy's Home Hemodialysis Setup



Sherry's Home Hemodialysis Setup



Rosie's Continuous Cycling Peritoneal Dialysis Setup



NPR Spotlight

Living out the “Be Prepared” Motto

During the monthly Network Patient Representative (NPR) Connection Calls, everyone is given an opportunity to connect with each other and the Network to share ideas focusing on a different topic. Recently, we talked about Emergency Preparedness and Kevin Dobbins shared about his Emergency Medical Bag. As a former Eagle Scout, he said this topic was perfect for him.

“I have been on hemodialysis since July 2018. Before that I had been on peritoneal dialysis since November 2016. I have been on and off dialysis since November 2013 and I have used all four dialysis ports at one time or another: peritoneal (twice), jugular, CVC Chest port (twice) and Hemo Arm port (current). I have been evaluated for a kidney transplant, but after review, I decided against trying to get a new kidney. I have Cystic Fibrosis (CF) (yeah, that is a whole other long story), and lots of 'quirky' medical issues related to the CF mutation. I have almost no immune system right now, so to start taking additional drugs to reduce it even further, would open me up to any respiratory infections, which in my current condition, would quickly kill me.

I have been married to my gorgeous wife, Donna, for almost 28 years. She is my "in-home nurse" who has learned enough medical knowledge to talk to my doctors at their level. Many people believe they have a Guardian Angel who watches over them. I married mine! We have three adopted sons, two dogs, and a pet Blue-Tongue Skink. I am retired due to my

Kevin Dobbins
Network Patient
Representative,
FMC-Tesson Ferry
Dialysis in St. Louis



medical issues, but worked as an independent computer consultant for many years.

I developed an emergency backpack, which includes a printout of my medical history so I am always prepared. The backpack is a regular laptop backpack my wife bought on Amazon. It has a combination lock at the top, to keep contents secure (although I have never used it). I added the Red Cross patch. I keep a bottle of water on the left pocket within easy reach. It has lots of pockets and plenty of room.



Kevin's
Emergency
Medical
Backpack

The backpack includes an emergency sugar packet, Jolly Rancher candy, Glucose tablets, a Pop-Tart (not pictured) for carbs, a mini First-Aid kit, face mask, eye mask (for naps), ear bud headphones, throw up bag, emergency inhaler (new in bag, a backup for the one in my pocket), Glucagon, binders, an oxygen sensor, Kleenex, and my insulin bag.

My Medical History printout includes:

- Personal Info (name, address, birth date, weight, height, BMI, blood type).
- Emergency Contacts and their names, phone numbers, and relationship. Plus, a statement that has my permission to speak for me and make decisions on my behalf if I am unresponsive.
- A BIG statement (in red and highlighted in yellow) that I have a dialysis graft in my left arm, and no blood pressure or needle sticks in that arm.
- A statement that I am diabetic. If unresponsive, check my left front pants pocket for a blood sugar meter, how to read the meter, and what to do based on a high number or a low number.
- A statement that I am on Hemodialysis, my treatment days, Clinic Manager's name and contact number.
- A copy of the latest monthly lab results from my dialysis clinic.
- A list of major medical conditions.
- A list of my allergies.
- A current medication list: name, dosage, when I take it, the doctor who prescribed it and the date I started taking it.

- A list of my doctors, address, phone number, after hours phone number and why I see each doctor.
- A list of hospitals I go to, why I go to each hospital, which doctor sees me at each hospital, and my patient identification number.
- A very detailed list of my medical history from recent to past. I list antibiotics given, why and for how long. Surgery details. Any medical procedures and what the results were. Dates I was in the hospital, which one and why. Dates of and types of vaccines I have been given. All procedures related to my dialysis ports. It is very detailed, and the entire printout runs about 12 pages.

Kevin would certainly make his Eagle Scout leader proud and we thank him for sharing. If you are interested in learning more about becoming a Network Patient Representative at your clinic, contact the Network and/or talk with your clinic social worker or manager.



My Network: Network Patient Representative

Resources for Patients by Patients

The End Stage Renal Disease (ESRD) National Coordinating Center (NCC) works with patients to make resources to help people live well with kidney disease. In 2020 they have worked to address several topics, including: home dialysis, infection prevention, kidney transplant and treatment choices. These resources and more can be found online at www.thekidneyhub.org or www.esrd.ncc.org.



Taking Care of Your Dialysis Access

Q & A on Self-Cannulation

Self-Cannulation is what they call it when you do your own needle sticks for dialysis. We asked a couple of our Patient Advisory Council members about their experiences doing their own needle sticks. Jeffrey Cauley and Dan Westcott both have been doing their own sticks for many years, Jeffrey for 20 and Dan for seven.

Why did you get started self-cannulating?

Jeffrey: “The staff kept infiltrating my access so I asked the expert nurse cannulator if she could help me learn to self-cannulate. I had been setting up my machine each treatment, so I figured I might as well try to do my own sticks too.”

Dan: “We were having some problems with my dialysis access. I was sent to visit the access center several times to get it checked and they would always say there was nothing wrong with it. The staff encouraged me to give self-cannulation a try, and it worked.”

How has doing your own needles sticks helped you?

Jeffrey: “I don’t get that many problems with infiltrations anymore, so I feel better. I also decided that I may as well try home dialysis, since I was already managing my own care at the center. The home dialysis staff have asked me to visit my old center and dialyze with my home machine there so other patients can see what it’s like to do home hemodialysis.”

Dan: “I have not had any more problems with my fistula. I haven’t had to go to the access center since I’ve been self-cannulating. I used to have lots of anxiety before dialysis. I worried about who was going to be taking care of me and who would be sticking my needles. Now, because I know I am in control of my treatment, I no longer take the anxiety medication I was taking before dialysis. Although I still have some anxiety, it’s nowhere near what it once was. Having to focus on doing my needle sticks takes away from the unpleasantness of the situation. It has helped me to feel more at ease at dialysis.”

“Doing your own sticks may not be for everyone, but it’s worth giving a try.” - Dan Westcott

Jeffrey Cauley currently does home hemodialysis at his home in Kansas with support from FMC-Parallel Parkway in Kansas City. He joined the Patient Advisory Council in January 2020.

Dan Westcott is currently on in-center hemodialysis at FMC- Salina where he is the Network Patient Representative. Dan has been on the Patient Advisory Council since 2016 and represented Network 12 on the National Kidney Community Emergency Response Patient Learning and Action Network since 2018.

Jeffrey
Cauley

Dan
Westcott



My Choices: What Should I Know About Fistulas
My Choices: Self-Cannulation

Support for Challenging Times

Living with and managing a chronic illness takes a lot of work, and having support from family, friends, peers and professionals can make a big difference. Even though we must social distance to stop the spread of COVID-19, we can still connect with others—just in a different way. Who would have thought we would be using services like Zoom to celebrate birthdays, doing “drive-by” graduations or video chatting with our grandchildren? One new Medicare benefit as a result of COVID-19 is telehealth services. Telehealth allows you to get your health care through online services. You no longer have to go to an office, but you can get services, such as mental health counseling, from the comfort of your own home. Talk with your social worker about mental health services in your area or visit www.mentalhealth.gov. Medicare Part B covers mental health services and visits. Below are some support groups available to connect with others.

National Help Lines and Support

National Kidney Foundation (NKF)

www.kidney.org

- Patient Help Line:
(855) NKF-CARES (653-2273)
NKFcures@kidney.org
- Peers Lending Support | www.kidney.org/patients/peers
(855) NKF-PEER (653-7337)

Renal Support Network

www.rsnhope.org

- Helpline (800) 579-1970
- Monthly Online Support Groups
(Registration is required)
 - Fourth Sunday of every month
4:30-6:30 p.m. CT
 - Second Tuesday of every month
6:30-7:30 p.m. CT

Facebook Groups*

Chronic Kidney Disease Support Group | www.facebook.com/groups/CKDSupport

Dialysis Uncensored | www.facebook.com/groups/DialysisUncensored

Home Dialysis Central | www.facebook.com/groups/HomeDialysisCentral

Kidney Disease, Dialysis, and Transplant | www.facebook.com/groups/2229039880

Kidney Disease and Diet Ideas and Help | www.facebook.com/groups/kidneyhelp

Peritoneal Dialysis Support Group | www.facebook.com/groups/peritonealdialysissupportgroup

Woman's Renal Failure Support Group | www.facebook.com/groups/womansrenalfailuresupport

* The groups listed were recommended by Network Patient Advisory Council members. Qsource is not responsible for the content of any of the Facebook groups listed. You must be signed into Facebook or create an account to connect with groups.

For more information on Telehealth and Medicare coverage of mental health care visit our website to download our [Telehealth Passport for Dialysis Patients](#) or www.medicare.gov/coverage/mental-health-care-outpatient.





Qsource ESRD Network 12
920 Main St., Suite 801
Kansas City, MO 64105

Vaccination Is Important for You!

Each year, thousands of adults in the United States get sick from diseases that could have been prevented by vaccines. Vaccination is especially important for those at higher risk for complications from the flu. This includes people 65 years and older, those with health conditions like asthma, diabetes, heart disease, kidney disease and cancer.

Talk to your doctor about getting the vaccinations recommended:

- Influenza (Flu) vaccine
- Zoster (Shingles) vaccine
- Pneumococcal (Pneumonia) vaccine
- Hepatitis B vaccine

For more information visit the Centers for Disease Control and Prevention website at www.cdc.gov.

For more information or flu resources, please visit cms.gov/flu. You can also visit vaccinefinder.org/find-vaccine to find locations near you that offer a flu shot.

"I do a lot to stay healthy, including getting vaccinated."



**DON'T WAIT.
VACCINATE!**



[Learn More](#)



My Life: Vaccines