

Kidney Connection



Published for the Renal Patients of Network 17

Each ESRD Network is a nonprofit corporation that operates under contract with the Centers for Medicare & Medicaid Services (CMS). The Network system was established to assist in



the improvement of the quality of healthcare services and quality of life for transplant and dialysis patients. There are currently 18 ESRD Networks across the United States. Most of the Network's outreach is accomplished through volunteers, healthcare professionals who deal with kidney disease, and patients.

Some of the members of the Network 17 Patient Leadership Committee, family members, and Network staff

These volunteers work through the Medical Review Board, the Board of Directors, the Fistula First Subcommittee, the Patient Leadership Committee, and the Network Coalition. Each ESRD Network organization's responsibilities include the quality oversight of the care ESRD patients receive, the collection of data to administer the national Medicare ESRD program, and provision of technical assistance to ESRD providers and patients in areas related to End-Stage Renal Disease.

The Network website www.esrdnet17.org contains information on patient support groups, treatment options, patient rights and responsibilities, emergency preparedness, Medicare coverage, fistulas, rehabilitation, complaints & grievances, and many other relevant ESRD issues.

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Western Pacific Renal Network, LLC

Northern California, Hawaii, Guam, Saipan and American Samoa

Patient Profile

Carl found out he had kidney disease when he was 9 years old and started receiving in-center hemodialysis soon after his 25th birthday. Although he felt that it was going to be tough, he was hopeful. And sure enough, he received a kidney transplant one-and-a-half years later right before Christmas. The transplanted kidney served Carl for four years and then he began to receive in-center hemodialysis again on a regular basis. He feels fortunate to have been given the opportunity at such a young age to receive a kidney. Although he has researched having another transplant and has considered doing peritoneal and home hemodialysis, Carl prefers in-center hemodialysis at this time. He has a fistula that he cares for by listening for the thrill, being careful not to sleep on it, and washing it right before needle insertion. As for the dialysis treatments themselves, Carl must eat properly to avoid feeling weak. This includes having an apple during treatment and some ice “to avoid feeling spacey and weird”. During dialysis, Carl prefers to watch TV rather than to read or sleep. His favorite programs are on the Animal Channel. He likes to talk to the dialysis technicians and other staff as well as neighboring patients. “I’m a mechanic.” Carl loves working on cars. He works at an auto retail parts store on Saturdays. His goal is to someday work full-time. As for coping, Carl says, “I flow with life.” He used to take cognitive-behavior classes, which he enjoyed, and feels counseling can be productive. Carl enjoys visiting friends and hanging out at home. He does yard work and housework, exercises some with his friends, and likes to take walks. He also likes baseball and fishing. Rosie is his constant companion. She’s a 4-year-old 85-pound Red Nose Pit Bull. “I love animals” and this dog Carl describes as beautiful and sweet.



Carl and his dog Rosie

ESRD Network 17 is filled with a variety of unique and special individuals. With every new edition of the patient newsletter, we spotlight one of our patients for others to read about and perhaps learn long term secrets and coping strategies.

If you have concerns or questions about your care, you or your family may talk with your dialysis facility staff, call Network 17 at 1-800-232-3773 for technical assistance in English or Spanish, and/or file a complaint or formal grievance with your dialysis facility, your local health department, or the Network.

California Health Department 1-866-784-0703

Hawaii Health Department 1-808-692-7420

Medicare 1-800-633-4227

Patient Leadership Committee — “PLC”

Mission Statement - The mission of the PLC is to improve communications and services between patients and caregivers in improving the renal care experiences, and to represent and advocate the patient’s point of view within the Network.



Goal Statement - The overall goal of the PLC is to strive to assist patients in receiving the highest quality care every time.

Values Statement - The PLC values every ESRD patient’s life and their ability to lead an optimum lifestyle.

Statement of Purpose - includes the Purpose, Goals, and Membership guidelines, and can be located on the Network website at www.esrdnet17.org. Click on Patients at the top and then on Patient Leadership Committee on the left.

The PLC functions in an advisory capacity to the Network and was instrumental in naming this newsletter. The PLC also functions in an advocacy role currently working on an education initiative (“The 3 x 5 Card Project”) aimed at increasing the level of health care knowledge and treatment participation of new and established ESRD patients. The group has created information cards that will be given to all patients. These 3 x 5 cards will soon be tested at various dialysis facilities before Network-wide implementation.

The PLC consists of the following officers (2-year terms):

- ◆ Chair - runs the meetings
- ◆ Vice-Chair - supports the Chairperson
- ◆ Project Coordinator - assists with membership
- ◆ Parliamentarian - advises the PLC on meeting regulations
- ◆ Historian - maintains records of all PLC activities
- ◆ Recording Secretary - distributes meeting minutes
- ◆ Outreach Liaison - forges relationships with other groups and the media

The PLC Steering Committee plans and manages the activities and direction of the PLC. It currently consists of the Chair, Vice-Chair, Project Coordinator and 2 members-at-large.

June 2008 marks the one-year anniversary of the PLC. Each year new members are added to the Committee. Plans continue to be worked on for initiation of a Pacific Islands PLC that will represent Hawaii, Guam, Saipan and American Samoa.

The Patient Leadership Committee is a subcommittee of the Network Medical Review Board (MRB) and is represented at all MRB meetings.



Dolores is a member of the Network 17 Patient Leadership Committee. She has been an ESRD patient since 2005 and currently receives in-center hemodialysis in San Jose, California.

Preparing for Emergencies

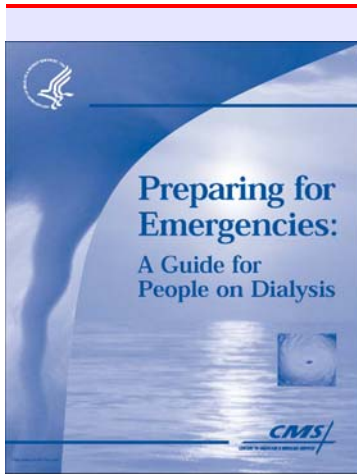
Emergencies caused by weather, earthquakes, fire or terrorist attacks can happen with or without warning. It is important to be prepared so you can feel better and stay healthier.

Tips for Preparing for an Emergency:

- ⇒ **Gather and Carry Important Medical Information** — If you must go to a different dialysis center or hospital for treatment during an emergency, or if you need emergency health care, the medical staff needs to know your medical status so you can get the right treatment. Therefore, keep your medical information and a list of your medications with you at all times, and give a copy to a caregiver or family member.
- ⇒ **Wear a Medical Emblem** — Order a bracelet that indicates that you require dialysis. Ask your nurse or social worker for information about ordering medical emblems.
- ⇒ **Make Alternative Arrangements** — For receiving hemodialysis:
- ◆ Make sure your dialysis center has your current street address and phone number, and emergency contact information.
 - ◆ Make arrangements for backup transportation to your dialysis facility.
 - ◆ Ask your facility staff about other dialysis facilities in your area to see if they provide the type of treatment you would need.
 - ◆ If you receive home hemodialysis or utilize Chronic Ambulatory Peritoneal Dialysis (CAPD) or use Continuous Cyclic Peritoneal Dialysis (CCPD), then be sure to plan for an emergency with your facility's staff.
- ⇒ **Maintain Extras** — Keep a supply of medicine at your work place or any place you spend a great deal of time, like a family member's home.
- ⇒ **Know What Emergency Diet to Follow if Your Dialysis is Delayed** — consult with your facility dietitian about an emergency diet plan; ask how to disinfect water. (Do not use water from a swimming pool or spa.)
- ⇒ **Know How to Get Off of a Dialysis Machine During an Evacuation** — Have your dialysis facility staff show you what to do if you are on a dialysis machine in an emergency to disconnect. Your access needles may need to be left in place until you get to a safe place. NEVER cut your access needle lines — you will bleed to death. If you have a catheter, your professional staff should assist you; do not try to disconnect yourself



- ⇒ **Know the Procedures if You Must Evacuate to a Designated Safe Area** — Wait for directions from the person in charge. Do not remove your fistula needles until you have been checked by medical personnel, or until you are sure you are in an area out of immediate danger. Under no circumstances should any medical personnel unfamiliar with your dialysis status place anything into your vascular access.



Request your own copy of the CMS publication "Preparing for Emergencies: A Guide for People on Dialysis" from the facility social worker.

Supplies to Consider for Your Emergency Preparedness Kit

- ___ measuring cups, teaspoons and tablespoons, dropper
- ___ plastic knives, spoons, forks
- ___ pack of napkins and paper plates
- ___ pack of plastic or styrofoam bowls
- ___ paper towels
- ___ pack of plastic cups
- ___ candles
- ___ matches
- ___ can opener (manual)
- ___ baby wipes
- ___ sharp knife
- ___ flashlight & batteries
- ___ scissors
- ___ garbage bags
- ___ plastic jug for storing water
- ___ 1 small bottle of household chlorine bleach
- ___ piece of cloth, cheese cloth, or handkerchief
- ___ strainer
- ___ extra pair of eye glasses (in case first pair breaks)
- ___ radio & batteries
- ___ first aid kit
- ___ 5-7 day supply of all your medicines
- ___ diabetic supplies (if necessary)
- ___ a week's supply of food and water



Helpful Tips During an Emergency:

- ◆ Stay at home unless you are hurt, as long as it is safe to do so. Instructions for dialysis patients may be available on TV, radio, or by phone or messenger. Depending on the nature of the emergency, consider calling your dialysis facility or doctor because they might be able to help you manage this emergency.
- ◆ Start your emergency diet as soon as an emergency situation is predicted or occurs if it appears that the emergency may delay your next regular dialysis treatment.
- ◆ If you must go to a shelter, tell the person in charge about your special health needs.
- ◆ Take a fanny pack or backpack stocked with emergency supplies, food, and medication with you if you will be away from home when severe weather or a natural disaster is predicted.
- ◆ Hospitals may not be able to give you maintenance dialysis treatments. No one should use your access to give you fluid or medication.

Preparing for Emergencies (continued on page 6)

The American Red Cross provides a free online training course at www.redcrossbayarea.org/pba to assist with emergency preparedness.

Once you complete your training, please enter the partner code **NW17**. Everyone who completes the training will receive a promotion code for 20% off disaster items at www.redcrossshop.org where prepackaged preparedness products can be purchased. These products include Emergency Preparedness Kits, First Aid Kits, Safety Tubes and reference guides that are ideal for individuals, homes, workplaces and vehicles.

In the event of an emergency, go to www.dialysisunits.com to find out the open / close status of any dialysis center and its location.



Marianne Hutton, RD
Co-author of “Kidney Friendly Comfort Foods”

Savory Breakfast Bread Pudding

8 oz lean ground pork
1 tsp ground sage

- 1/2 teaspoon *each* granulated garlic, dried thyme and ground fennel
- 1/4 teaspoon *each* ground black pepper and red pepper flakes
- 1 pinch ground cloves
- 1 medium onion, thinly sliced
- 1 medium red bell pepper, thinly sliced
- 4 cups fresh bread cubes
- 6 eggs
- 2 cups soy milk
- 2 Tbsp. grated low-sodium parmesan cheese

Preheat oven to 350 degrees F. Generously coat a 9 inch x 13 inch baking pan with butter-flavored cooking spray. Combine ground pork and spices. Brown pork in a large skillet coated with cooking spray over medium heat

Word Search

L E A F B E H S C Y L C D Q O
 C A R D A O C U Q F T I P I Q
 T S E J Q M G P I R N K D N F
 U F N P X F I P Q P L A H K J
 A B O W Z J W L E N R D Z U B
 M G H R W W G Y Y J E A B A C
 A V P O G A U K B P O T C N W
 F K L A H W H I H N L K S J L
 Y I P U Z E M T K U P A E I N
 M E E T I N G P L A C E N N L
 B M J Y D O S L C Y T E F A S
 G U J C A L M K M L O L K J C
 E N O D L S W K E H F N L T L
 H C H P V Q E J M I Q S L J S
 A F M E L B M E L A C I D E M

Words to find:

- | | | |
|------------|----------------|--------|
| Backpack | Meeting Place | Listen |
| Calm | Radio | Safety |
| Phone | Family Plan | |
| Supply Kit | Medical Emblem | |

until no longer pink. Remove from pan, cool slightly. Coat skillet with cooking spray and cook onions and peppers until softened, about 5 to 6 minutes; add to browned pork. Spread bread cubes evenly in baking dish; top with pork and sautéed vegetables. Whisk together eggs and soy milk; pour over bread mixture, pressing lightly to soak in. Sprinkle top with grated parmesan. Bake 45 minutes until set and top is golden brown. Makes 12 servings.

Nutrient Analysis per 1/2 cup serving: Calories 160 Kcals, Protein 10 g, Carbohydrates 12 g, Fiber 1 g, Total Fat 8 g, Sat Fat 3 g, Cholesterol 120 mg, Phosphorus 131 mg, Sodium 152 mg, Calcium 65 mg, Potassium 196 mg

Altruistic Living Donation by Kidney Transplant Recipient Shar Carlyle

What is the motivation to share your transplant story? I have received a gift of life. How can you *not* want to help other individuals with renal failure? Since losing both my father and my youngest brother in the prime of their lives to Polycystic Kidney Disease (PKD), I've heard from many other families impacted by two or more generations of PKD. Experiencing deep personal loss planted a little seed in my mind, "What if other families did not have to suffer similar losses? Are there transplant options? What if we could change this?"

Why did you need a kidney transplant? I was born with PKD. It's a life-threatening genetic disease affecting over 12.5 million people worldwide.

Why did you seek an altruistic living donor? No one within my loving circle of friends and family was a match. I knew I could lead a full and productive life with one good, working kidney. My donor, Sally Kennerson, a mother of three, and I found each other through Matchingdonors.com, a nonprofit agency out of Canton, MA. She gave me one of her kidneys and asked for *nothing* in return but to lead a healthy life. She is currently on active duty in the Air Force Reserves.

Why seek an altruistic donor? Isn't the national wait list enough? Nationwide there are 98,992 organ transplant candidates on the UNOS wait list (06/05/08, www.unos.org). Of these, only 4,471 received transplants in the first two months of 2008. What these numbers don't tell us is how many folks suffer debilitating health complications while awaiting a life saving organ transplant.

Any suggestions to others considering living donor transplant? Yes...

- 1) First, learn *your* transplant center's rules. As this is new, some hospitals have differing opinions within their own staff.
- 2) Familiarize yourself with your hospital's...
 - a) Protocols such as pre-transplant (testing one donor at a time or multiple donors?)
 - b) Surgical methods (such as nephrectomy or no nephrectomy? Laparoscopic?)
 - c) Medicine protocols (steroids or steroid-free protocol)
- 3) Check your wait list status periodically.
- 4) Begin a donor search. Put the word out that you are in need of a life saving organ. I was uncomfortable asking for a kidney for myself, but was okay putting the word out for my middle brother.
- 5) Explore innovations in transplantation such as paired donation.
- 6) Seek a transplant coach or mentor, someone in your family or in the transplant community who is willing to go through the process with you.
- 7) Line up help at the other end. When you come home, you will need it. Whether it's making you food, filling your pill box or taking you to bloodwork and transplant clinic appointments. It's a time of recuperation and healing.



Transplant recipient Shar with her altruistic living kidney donor Sally

Network Goals

- ⇒ Improving quality and safety of dialysis related services for individuals with End-Stage Renal Disease
- ⇒ Improving independence, quality of life and rehabilitation through transplantation, use of self-care modalities, and in-center self-care
- ⇒ Improving patient perception of care and experience of care as well as resolving patients' complaints and grievances.
- ⇒ Improving collaboration with providers to ensure achievement of the goals through the most efficient and effective means possible
- ⇒ Improving the collection, reliability, timeliness and use of data to measure processes of care and outcomes

ESRD Network 17



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Kidney Connection is on the Network website
www.esrdnet17.org

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Core Values

Open Communication
Making a Difference
Commitment
Ethics
Respect
Caring
Fun

www.esrdnet17.org

Mission

To facilitate improvement of quality of care provided to ESRD patients.

Serving Northern California,
Hawaii, Guam, American Samoa
and Saipan
as ESRD Network 17

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