

PATIENT NEWSLETTER

ISSUE 3
JULY 2016

The Role of the Networks

How We Work for Patients

The End Stage Renal Disease Networks are companies that work under contract for the agency that runs Medicare, Centers for Medicare & Medicaid Services (CMS). There are 18 ESRD Networks throughout the country. ESRD Networks 8 and 14 work together as the Alliant Quality Kidney Collaborative (AQKC) to improve the quality of healthcare, and the quality of life for ESRD patients in Alabama, Mississippi, Tennessee and Texas. Some of the ways we serve you include:

- Providing educational materials to patients and staff
- Working with dialysis facilities on projects to improve your care
- Investigating and resolve grievances
- Providing information about the different treatment options available to you
- Working with patients who are having a hard time keeping or finding a dialysis facility

If you would like more information about your Network, you can visit our website at <http://aqkc.org/>.

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Dialysis Facility Compare

Dialysis Facility Compare is a website that gives you information about Medicare-certified dialysis units. This information can help you choose the best regular dialysis unit for you, or if you need a unit when traveling. The more information you have, the easier it is to make the best decision about your care.

What can I learn about a facility from the website?

- ◆ Types of dialysis offered (hemodialysis, PD, home hemodialysis)
- ◆ Number of hemodialysis stations
- ◆ Address and phone number
- ◆ The days and times dialysis is offered
- ◆ Facility ownership
- ◆ How long the facility has been open
- ◆ The Star Rating

What quality measures can I learn about?

- ◆ Percent of patients who had enough wastes removed from their blood during dialysis
- ◆ Percent of patients who have their anemia under control
- ◆ Percent of patients who have their calcium under control

Continued on next page

Dialysis Facility Compare *(continued)*

- ◆ Percent of patients with a fistula or catheter
- ◆ Patient survival rate
- ◆ Patient hospitalization rate

How do I use the website?

- ◆ Go to www.medicare.gov and select “Compare Dialysis Facilities in Your Area”.

- ◆ Choose a search method. You can search by facility name, zip code or within a state or county.
- ◆ Once you have chosen the area, select the dialysis facility you would like to get more information about. If you choose more than one facility, you will be able to compare their information and decide which unit is best for you.

Vaccination and Immunization: Why are these important?

The terms “vaccination” and “immunization” are often used interchangeably. We hear both terms in the news, in social media, at work, or in casual conversations with friends and family. But, do we really know what they mean? And most importantly, are we really protected against the diseases they claim to prevent?

Vaccinations and immunizations are related, but they are not the same. According to Oxford Dictionaries, to “vaccinate” is defined as the action of treating with a vaccine (giving a shot), with the intent to produce immunity against a disease. However, “immunization” is the action of making a person immune to infection or a disease, using a vaccination (or a series of vaccinations). Simply put, a person can be vaccinated, but not necessarily stay immunized against a particular disease, so it’s important to stay informed on when and how often to vaccinate.

So, why should I vaccinate? The best way to stay informed and protected, is to consult with your physician or healthcare team on

what vaccinations are recommended for you. Factors to consider include age, underlying health conditions or diseases and some medical treatments. Some people can be more prone to disease than others, such as those undergoing dialysis or cancer treatment.

What about safety? There have been many studies that show the safety of vaccinations. Vaccine recommendations are determined after extensive research, studies and clinical trials before they are considered safe for public use. According to the Centers for Disease Control and Prevention (CDC), some diseases have become extremely rare due to vaccinations. For example, in 1974, Japan had a whooping cough (pertussis) epidemic, with 13,000 reported cases in the country. Japan was able to reduce the epidemic by vaccinating nearly 80% of the country’s children. The year after the vaccinations, only 393 cases of whooping cough were reported.

Until we find ways to completely eliminate certain diseases, it is important to keep vaccinating and immunizing.

If you have questions please talk to your

physician or healthcare team. Learn as much as you can about immunization schedules and recommendations, so you and your family can stay protected.

If we are all more proactive about vaccinations, less people will become infected, and the chances of spreading disease will contin-

ue declining over time. This will not only protect our health today, but also the health of generations to come.

Visit our website at www.esrdnetwork8.org to learn more about our vaccination initiatives and resources.

Patient Experiences with Different Treatment Modalities

Precious McCowan



In 1994 I was diagnosed with Type 1 Diabetes, I must admit that my blood sugar levels were not controlled, and later led to hypertension. By 2010, I was faced with End Stage Renal Disease (ESRD). I was in denial for several months, until April 2010, I

was hospitalized and had to receive emergency dialysis, which became one of the most fearful and concerning moments of my life. I remember several Nephrologists speaking to me about treatment options that were suitable for my busy life, after researching peritoneal dialysis and its stipulations; I decided that hemodialysis would work best for my schedule. I know most would think that peritoneal or home dialysis is the better choice for someone with an active lifestyle, but not for me. Although my family is supportive, I have always been an independent person and at the time did not want to be a burden or put any pressure on my loved ones with their availability to assist me with home dialysis treatments yet; while receiving hemodialysis I was often very sick. My Nephrologist, Dr.

Long Tran, has always been concerned and considers my sensitive health conditions, he has provided healthy methods and advice to help restore my health.

By the grace of God I was only on hemodialysis for four month before I received a kidney and pancreas transplant in August of 2010. For me this was a new beginning! For seven months, my transplanted kidney and pancreas were functioning very well until my son unexpectedly passed away; my husband and I knew we had to be a blessing to someone else that was in need of a transplant, so we decided to donate our son's organs. Unfortunately, a day after my son's passing I became very ill and stressed and was hospitalized. My body began to reject the transplanted kidney and pancreas and both had to be removed. So now I am back on hemodialysis, yet I may consider giving Nxstage home dialysis a try because of better quality of health and freedom patients acquire. I'm hopeful that Nxstage dialysis treatments will allow the time and energy to attain my Master's Degree in Behavior Science. Only one more year to go!



Anna Gonzalez

I was diagnosed with ESRD with a kidney function of 8% in October of 2000, due to hereditary Diabetes Type1 and Hypertension.

I received a call from my Nephrologist's office, per doctor's request, to consult with a doctor as soon as possible. My heart told me it was not good news, but determined to think positive and hope for the best. The Doctor suggested preparing me for dialysis with a graft or a fistula. I replied, "Absolutely, but it will have to wait until the first of the year." I did not comprehend the graveness of this horrible disease. The doctor looked at me with a concerned look on his face. In the end, I was able to convince him to allow me to wait.

Fortunately, I was not able to keep my commitments (traveling out of the country) and became terribly ill and rushed to the ER and hospitalized for 2 weeks. A couple days later I was dialyzing with a temporary catheter in my neck. God was with me.

On January 10, 2001, I began my dialysis journey. I was determined to stay positive, even though it was difficult at times. I was placed on the transplant list and was told the

wait for a transplant would be from 3 to 5 years. I was very hopeful and waited patiently.

Meanwhile, I wanted to learn more about my health care so, I educated myself as well as my fellow patients. My faith kept me going. I felt it was a calling from God for me to give back to fellow ESRD patients as well as my loved ones.

By the 5th year of being on dialysis and waiting for a transplant, I was feeling a little discouraged and physically drained. My faith kept me going. Three years later, on April 19, 2008, I received a phone call from the transplant center telling me "this one is for YOU!" I felt so very happy, blessed and of course, very grateful to the donor family. At the same time, I couldn't help feeling much sadness for them. They know their daughter lives in me as well as other recipients that received her organs. "Gift of Life"

I truly believe I am here through the Grace of God. A transplant, I believe, is a tradeoff that we must learn to deal with different issues from dialysis, and of course, I am so grateful and cherish my kidney, which by the way, her name is "FIESTA". My transplant team and I named her. And yes, on April 19, 2016, my "FIESTA" turned 8 years. Thank you Lord!

AAKP to hold National Patient Meeting in Nashville

The American Association of Kidney Patients (AAKP) hosts a national patient meeting for kidney patients and their family members. This year, the meeting will be held in Nashville, TN, on September 23—25, at the Nashville Airport Marriott. The meeting will provide sessions for patients at all stages of kidney disease. To learn more and register for the meeting, visit the website at www.aakp.org or call (800) 749-2257, and choose option 7, Ext. 2 or 5.

The Grievance Process and You *

If you are unhappy with the care or treatment you receive at your dialysis clinic or transplant center, you have the right to file a grievance. Here's how to file your grievance:



FIRST — talk to your nurse, doctor or social worker about the problem. There could be a simple explanation. Or, it may be possible for you and the clinic to work out a solution that could result in better care for you and other patients.

NEXT — if talking does not resolve the issue, or if you feel you cannot discuss your problem with the staff at your clinic, you can go directly to the regional administrator, or the corporate office of your dialysis company or transplant unit. The names and phone numbers of these contacts should be posted in the waiting room of your clinic.



FINALLY — if none of the above actions work or if you feel your clinic or corporation cannot assist you, call your ESRD Network or State Survey Agency toll-free for help.



Network 8, Inc.
1-877-936-9260

State Survey Agencies

Alabama
1-800-356-9596

Mississippi
1-800-227-7308

Tennessee
1-877-287-0010

The Network staff is authorized by the Medicare program to receive, investigate and resolve grievances made by or on behalf of ESRD patients in your area, when possible. When you file a grievance, your case will be assigned a category to determine severity. Based on that category, things are set such as how long the case is open, whether our quality RN should be involved, if records should be requested from the facility and if referrals need to be made. It is our responsibility to review all information available and/or make referrals. If quality is the concern, the Network might request that the facility correct the problem, or ask the State Survey Agency to determine the course of action. Either way, the Network is advocating for you.*



*or your representative

Very Berry Bread Pudding

www.freseniuskidneycare.com



Nutrition Per Serving:
 Calories 361; Total Fat 23 g; Saturated Fat 13 g; Trans Fat; 0 g; Cholesterol 192 mg; Sodium 171 mg; Carbohydrates 31 g; Protein 8 g; Phosphorus 128 mg; Potassium 157 mg; Dietary Fiber 1.8 g; Calcium 84 mg.

Serves 10 (1 serving = 1 cup portion)

Ingredients:

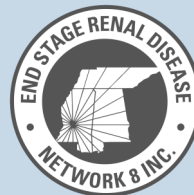
8 cups cubed challah bread
 6 eggs, beaten
 2 cups heavy cream
 12-ounce bag of frozen berry medley, thawed
 ½ cup sugar

2 tablespoons vanilla
 1 tablespoon orange zest
 ½ teaspoon cinnamon
 Whipped cream

Directions:

Preheat the oven to 375° F.

1. Beat eggs, sugar, cream, orange zest, vanilla and cinnamon until smooth.
2. Mix in bread cubes and fruit with hands.
3. Pour into buttered/greased pan and bake covered in foil for 35 minutes. If using butter, make sure it is unsalted.
4. Remove foil and bake for 15 additional minutes.
5. Turn off oven and let sit in oven for 10 minutes.
6. Cut, then serve topped with whipped cream.



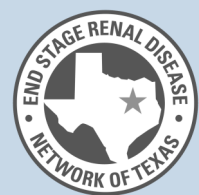
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