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# Renal Outreach

## Living with Renal Failure

by Della Major

**I**t all started in 2005, when I was told that I had an auto-immune disease that was attacking my kidneys. At first, I did not understand what Lupus was and how it could affect me so much. Upon completing my research, I realized that my battle had just begun. For five years, I refused to accept that I had a medical challenge such as renal failure. When I heard the word “failure” spoken to me it was hard for me to accept. I was the person who believed that “failure” was not an option. I believe nothing was impossible to overcome and with God all things are made possible.

In 2010, I was told by my physician that I would have to start dialysis. In the beginning I thought dialysis meant the end of my life, and I believed that the life that I once lived would never be the same. I also thought that I was in this battle alone. How untrue this really was! I quickly found out that I was not alone, but instead I gained a new family and a new set of friends that were irreplaceable.

My dialysis technicians and nurses turned out to be the life source that I needed to help me overcome my fear and my grief. At my dialysis center, there are a team of staff members willing to go the extra mile to make sure that you are comfortable in every possible way. At my center, patients come first and patient care is the most important thing. We are treated with love and respect. In addition, we are treated like family. My dialysis team makes sure the patients know they are not alone and they are there for us.



This newsletter The Renal Outreach is one way patients can stay up to date on Network activities and projects. If you are not already on our mailing list, you may sign up to receive The Renal Outreach free of charge. To subscribe, call the Network at 1-800-456-6919 and ask for Katie Stark. Or visit <http://www.therenalnetwork.org/resources/newsletters.php>.

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At the beginning of my treatments, it was quickly evident that I really was not alone. I gained new friends who understood what I was going through. As a very independent person, it was difficult accepting illness, but once I realized that I was not alone, I began to have a new focus in my life. My focus now is on living my life to the fullest.

Living with renal failure does not mean the end of your life, but instead the beginning of new hope. Every day that I go to work, I am overwhelmed by the compliments from my peers on how well I am looking. I attribute this success to my commitment to attend every dialysis treatment. There are times where I am weak after a treatment, but with a little rest I am ready to conquer the world. In the summer, I travel overseas, to other states and even the Caribbean! The convenience of having dialysis centers everywhere allows me to continue on with life as normal. I realize that everyday people face battles and challenges that often rock their world, some may even appear that they can only end in failure, but I learned that all things are possible to overcome and that you are not alone. Renal failure does not mean the end, you can make it the beginning of a second chance like I did.

Each day organizations like The National Kidney Foundation (1-800-522-9559, [www.kidney.org](http://www.kidney.org)) and The Renal Network along with your dialysis care team are helping people maintain the lifestyle they used to have before ESRD. You too can quickly learn that life as you once lived is yet attainable. All you have to do is just believe! Life is not over yet! How do I know, just wait and see.

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The 5 Diamond Patient Safety Program helps dialysis units develop a “culture of patient safety.”

This means that all of the staff members in the dialysis unit go about their jobs in a way to keep patients safer from medical errors.

Participation in the 5 Diamond program is free. All the educational materials are online. Dialysis facilities can sign-up on their own and download the materials, and teach their staff members about different aspects of safety.

The program is divided into 15 different topic areas, called modules. Each module focuses on a specific area for patient safety. Modules include:

- ◆ Patient Safety Principles
- ◆ Communication
- ◆ Constant Site Cannulation
- ◆ Decreasing Patient & Provider Conflict
- ◆ Emergency Preparedness
- ◆ Flu Vaccination

- ◆ Health Literacy
- ◆ Infection Control
- ◆ Medication Reconciliation
- ◆ Missed Treatments
- ◆ Patient Self-Managed Care
- ◆ Sharps Safety
- ◆ Slips, Trips & Falls
- ◆ Stenosis Surveillance
- ◆ Transplantation

Here is how the program works. Once a unit decides to participate, the facility staff in charge can

download the information for each module. They will work on an in-service education for all staff members on the module topic area. When completed, they submit the finished module to the Network office, and for this accomplishment they are awarded a “diamond” certificate. If a unit completes five modules within 12 months, they are awarded a 5 Diamond Patient Safety status and receive a plaque to display for all to see.

So, check with your dialysis staff members to see if your unit is participating in the 5 Diamond Patient Safety program. If the answer is no, suggest that they visit [www.therenalnetwork.org](http://www.therenalnetwork.org) and look for the link to the 5 Diamond Safety Program.

## The Network’s Process for Patient Grievances

The Renal Network, Inc. is available to assist you in resolving a grievance or concern you may have about the quality of your care at your facility. For this reason, it is required that our contact information and your State Survey Agency’s information be posted in your facility. We are just a phone call away and can offer assistance in a number of areas, in addition to ways of addressing grievances. Although you are welcome to contact us at any time, we encourage you to maintain open communication with your health care team and to talk about your concerns as they come up. If talking through the issues does not seem to resolve the problem, you have the option of filing a grievance with your facility. Each facility is required to have a process for responding to grievances filed by a patient.

Some patients wish to file a grievance with the Network before working with their facility, and

others contact the Network after their efforts to resolve an issue at their facility have been unsuccessful. The Network can offer you guidance on your options, coach you on how to advocate for yourself and provide education on your rights as a patient. You may remain anonymous or ask us not to contact your facility. However, with your consent, the Network can investigate your grievance in more detail, make suggestions to the facility to resolve issues, and assist the facility to take corrective action if necessary.

The Network tracks all grievances regarding facilities and works with facilities to address patient concerns. In addition, the Network will follow up with you to make sure your issue has been addressed. Your quality of care is very important to us.

***To file a grievance please contact us at:***

Phone: 1-800-456-6919

Email: [info@nw10.esrd.net](mailto:info@nw10.esrd.net)

Write: The Renal Network, Inc. 911 E. 86th St.,  
Ste. 202 Indianapolis, IN 46240

# Treatment Options: You Do Have Choices!

This spring The Renal Network (TRN) convened a meeting with patients who pointed out that they were not aware of their treatment options when they first began dialysis. Several of these patients



stated that it was through their peers and TRN, not their doctor or the medical staff, that they learned there were options besides in-center hemodialysis.

Although in-center hemodialysis may be a good choice for people, there are other options that may allow patients more freedom and independence, such as home dialysis. Doing dialysis at home may be a good fit for your lifestyle and needs. The following are the types of dialysis that are considered “home therapies.”

**Peritoneal Dialysis (PD)** – There are two types of PD- Continuous Ambulatory Peritoneal Dialysis (CAPD), which is done during the day, and Continuous Cycling Peritoneal Dialysis (CCPD), which uses a cycler at night. PD uses a catheter in the abdomen, and the patient’s own abdominal membrane (or peritoneum) filters fluids and waste from the blood. There are fewer dietary restrictions for PD patients.

**Home Hemodialysis** – You need a partner for this, and you and your doctor will determine how many times a week you dialyze. Home hemodialysis is usually conducted 5-6 days per week but treatment times may be shorter than in-center. Dietary restrictions are fewer and patients report a better quality of life. Patients can dialyze more on their own schedule in the comfort of their own homes.

**Nocturnal Home Hemodialysis** – Nocturnal dialysis is performed while the patient is sleeping. Nocturnal dialysis can also be done in-center. Nocturnal dialysis may allow those who are working or have other obligations to fulfill during the day more time and flexibility to do so.

**Transplantation** - requires no dialysis, but does not cure you of kidney disease. Medication must be taken to ensure the transplanted kidney remains healthy. If you are not already on a transplant list, talk to your health care team about this option.

**Self-care Activities** - Finally, in-center patients can increase their independence by learning self-care activities, such as self-cannulation while dialyzing in the facility.

Be sure to discuss all your treatment options with your health care team. Becoming educated about all of the available options may lead to a change in treatment modality that is a better fit for you.

## Dialysis Facility Compare

Dialysis Facility Compare is a website that provides information about Medicare-certified dialysis facilities. The site can be used to search for a facility in your area or to find out information about a specific facility. The site is hosted by CMS, and the website address is [www.medicare.gov/dialysis](http://www.medicare.gov/dialysis)

To find a dialysis facility, you can search by location – entering a zip code, city or state, or you can search by the dialysis facility’s name. The information provided includes:

- address and phone number of the facility
- whether there are shifts starting after 5p.m.
- the number of treatment stations
- if the facility provides peritoneal dialysis
- if the facility provides home hemodialysis training

Dialysis Facility Compare also provides quality measures information that is updated quarterly. Quality measures can be a tool in helping you make a decision about the quality of care at a particular facility. These measures show you how a facility is performing and provide information that can help patients avoid hospitalizations and death. The two categories measured are Best Practices and Hospitalization and Deaths. The subcategories under Best Practices measure the following:

**Anemia Management** – percentage of patients that have anemia under control

**Dialysis adequacy** – percentage of patients who had enough wastes removed from their blood

**Vascular Access** – percentage of patients using an AV Fistula

We encourage you to use this website when searching for a new facility or a transient facility when traveling. It is an easy way to access information on facilities.

You can also speak with your facility social worker or contact The Renal Network for assistance (1-800-456-6919) if you do not have access to a computer.

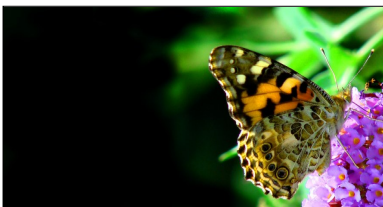
Going Out to Eat?

Take Your Phosphorus Binders with You!



Phosphorus binders work while food is in your stomach to “bind” the phosphorus so it can be eliminated from your body.

They must be taken immediately before or during the meal or snack.. Restaurant foods are often high in phosphorus, so don’t forget your binders!



## Quality of Life

Regardless of our circumstances, each of us needs to experience a level of enjoyment and comfort which gives quality to our lives. Quality of life matters, and for the dialysis patient there are some circumstances that impact that quality. For example, the dialysis schedule and its frequency may get you down. Or you may have more days that you feel ill and/or depressed. And of course the dietary restrictions that seem to limit or restrict the foods and fluids you like best can be frustrating. These and other issues may seem overwhelming to you at times and you might start to question the quality of your life. (continued on pg. 6)

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The good news is that there are several things you can do to feel better about your life as a person who happens to have kidney disease. One positive step can be to take more personal control of your life and be involved in your care. For example, talk with your social worker about a special questionnaire that helps kidney patients focus on quality of life issues. The “KDQOL” (Kidney Disease Quality of Life) questionnaire poses 36 questions that measure your thoughts about your physical and mental health in your daily life with chronic kidney disease.

Here are suggestions that other patients have found helpful to improve their quality of life:

**Educate yourself about treatment options.** These include hemodialysis, both in-center and home hemodialysis, peritoneal dialysis, nocturnal dialysis, and transplant. (*see our article on page 4*).

**Seek out social support.** It is important to connect with family and friends and maintain connections you have with church, volunteer work, or other groups. You should also check if your dialysis facility, local hospital, or your community has a support group.

**Ask for help!** Depression and anxiety are very common among dialysis patients. Forty percent of dialysis patients have depression at some point. It can be treated and you may find a support group or counseling helpful.

**Set a goal.** This could be a daily goal of something you want to accomplish that day or it could be a long-term goal. Goal-setting helps you to have a plan for the day as well as for the future.

Setting goals can help you feel more in control of your life.

**Start an exercise program.** It can help lower the fatigue and weakness that come with dialysis and helps with stress. Talk with your doctor or social worker before starting an exercise program.

**Explore your spirituality.** Spirituality may include connecting to church and/or other religious groups. It may also include prayer, meditation, relaxation, or keeping a daily gratitude journal. Spirituality may provide a key to coping and personal well-being.

**Work if you are able.** It can help with expenses as well as with your feelings of independence and self-worth. If you’re working or considering going to work, you and your social worker can review re-

sources to help you. See contact information on this page for more information about your state’s vocational rehabilitation program.

**Consider volunteering in the community or helping new dialysis patients feel welcome.** Opportunities like TRN’s Network Patient Representative Program may be a good option.

**Take a class that interests you** and helps you to focus on other interests. Perhaps a college or community class such as photography, art, theater, or a yoga class. You might consider topics such as Positive Attitude, Anger Management, Stress Management, or Organizational Skills. There are also web-based classes available. Remember, your decision to act is critical because you have the ability to positively affect your current quality of life. If you want a better quality of life talk to your social worker, doctor or other

*One Positive Step can be  
to take more personal  
control of your life and be  
involved in your care*

dialysis facility staff for guidance and ideas that may be helpful in your personal situation. As always, The Renal Network is available to help answer any questions or concerns you may have. Just call 1-800-456-6919.

<b>State Vocational</b>	<b>INDIANA</b>	1-800-372-7172 Toll-Free
<b>Rehabilitation Programs</b>	Family and Social Services Administration	1-502-564-4440 Local <a href="http://ovr.ky.gov/">http://ovr.ky.gov/</a>
<b>ILLINOIS</b>	Division of Disability and Rehabilitative Services	<b>OHIO</b>
Illinois Department of Human Services	Vocational Rehabilitation Services (VRS)	Ohio Rehabilitation Services Commission
Division of Rehabilitation Services	1-800-545-7763 (Toll-Free)	1-800-282-4536, ext. 1483 (Bureau of Vocational Rehabilitation)
1-800-843-6154 24-Hour Hotline (English or Spanish)	1-317-232-1427 (TTY) <a href="http://www.in.gov/fssa/ddrs/2636.htm">http://www.in.gov/fssa/ddrs/2636.htm</a>	General Information: 1-614-438-1252 Voice/TTY (In Ohio)
1-800447-6404 TTY	<b>KENTUCKY</b>	1-800-282-4536 Voice/TTY (Outside Ohio)
<a href="http://www.dhs.state.il.us/page.aspx?item=29737">http://www.dhs.state.il.us/page.aspx?item=29737</a>	Kentucky Office of Vocational Rehabilitation	<a href="http://rsc.ohio.gov/">http://rsc.ohio.gov/</a>

## Exciting Changes at The Renal Network !

The Renal Network has a new set of patient-centered goals for 2013. The new Statement of Work, or SOW, is designed to result in improvement in the quality of care for patients with ESRD with an emphasis on including “the patient’s voice.”

One of the exciting activities the Network is doing this summer is launching a new program for patients called the Network Patient Representative Program (NPRP). The NPRP provides a structure that will bring the patient’s voice into focus while opening communications between patient and patient along with enhancing communications between patients and the dialysis provider facility as well as with The Renal Network. This emphasis on including the “patient’s voice” as an active member of their own health care team will help engage patients and family at the facility level to foster positive changes.



We are also promoting patient and family involvement at the Network level by having patients participate in Learning and Action Networks (LAN) alongside facility staff and other renal professionals. These patients are considered subject matter experts, and their work will include developing educational materials and campaigns on a variety of topics chosen by the LAN.

The input from the patient experts, their family members and caregivers will help guide Network activities and promote best practices in the future.

The Renal Network  
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Suite 202  
Indianapolis, IN 46240

*Renal Outreach is a publication by The Renal Network, Inc. and is a newsletter for individuals and their families living with chronic kidney disease. The Renal Network works to facilitate the achievement of optimal wellness for renal disease patients, including those on dialysis or who have received a kidney transplant.*

## ADDRESS SERVICE REQUESTED

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# Have You Seen This Certificate Posted in Your Dialysis Facility?

This is a Quality Incentive Program (QIP) Performance Score Certificate. This CMS program evaluates dialysis facilities annually on their performance in specific areas and compares them to previous year's performance and to the national averages. This evaluation affects the Medicare payments sent to dialysis facilities each year. Your facility's performance this year (2013) will affect its Medicare payments in 2015.

All dialysis facilities are required by law to display its current certificate in a public area. The current certificate shows how well your dialysis facility did in 2011 in the areas of Anemia Management and Dialysis Adequacy. Anemia Management measures the amount of hemoglobin in your blood and Dialysis Adequacy measures how well your treatments are cleaning your blood.

Do you know what your most recent URR or Kt/V were? Do you know what your most recent hemoglobin was? Your numbers directly affect the cumulative numbers of your facility so you are partners in performance. Check with your dialysis staff members on what you, with their guidance, can do to improve your numbers.

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES  
CENTERS for MEDICARE & MEDICAID SERVICES  
End-Stage Renal Disease Quality Incentive Program  
2013 Certificate of Dialysis Facility Performance - Part 1  
Facility CMS Certification Number: 999999

**Certificate of Dialysis Facility Performance**

This Facility Meets 2 of 2 Quality Standards

<b>TOTAL PERFORMANCE SCORE</b>	30 out of 30		
<b>National Average</b>	29		

MEASURES OF QUALITY	FACILITY SCORE	NATIONAL AVERAGE	MEETS STANDARD
<b>Anemia Management: (Shows how well a facility keeps red blood cell counts at an acceptable level)</b>			
Percentage of patients with hemoglobin greater than 12 g/dL	10 of 10	10 of 10	Yes
<b>Dialysis Adequacy: (Shows how well a facility cleans blood during a dialysis treatment)</b>			
Percentage of patients with urea reduction ratio of at least 65%	10 of 10	9 of 10	Yes

Facility Name and Address: SAMPLE FACILITY, FACILITY ADDRESS, CITY, STATE ZIP CODE

Facility Medical Director: \_\_\_\_\_

Patrick Conway, M.D., M.Sc.  
CMS Chief Medical Officer  
Director, Office of Clinical Standards and Quality

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