



# RENAL ROUNDUP

For Patients in the Intermountain End-Stage Renal Disease Network (ESRD Network #15)

SPRING 2011

## Taking Charge of Your Life

By Christine Nguyen, Utah Member  
Network #15 Patient Leadership Committee

Taking charge of your life means taking charge of your illness, too. Here are the **10 "Be's"** that I do to take charge of my health and treatment. They may help you, too:

- **BE COMMITTED:** Follow your treatment prescription. Show up for appointments on time, every time. It may be tempting, but don't ask to be taken off treatment early.
- **BE CURIOUS:** Ask questions about your illness, its effects and different treatment options that are available to you.
- **BE PROACTIVE:** Ask "What else can I do to help improve my condition?" Your doctor and dialysis care team will be glad that you asked because they know that you are going to take care of yourself.
- **BE PREPARED:** Make and keep an updated list of your medications and allergies, and bring it with you everywhere you go.
- **BE AWARE:** Pay attention to how you feel. Write down any symptoms you experience, along with how often they happen, so that you can ask the nurse or the doctor about them.
- **BE ACTIVE:** Check with your doctor first, but try to exercise regularly to keep your energy up and reduce stress. Set a schedule to go for a walk. It may be

hard at first, so start by going around a block. Then increase the distance gradually. You will be surprised at how far you can walk (I walk outside or on a treadmill at least 3 times a week, for 30 minutes each time.)

- **BE PROUD:** Remind yourself that your survival instinct is strong. So whatever comes at you, deal with it one step at a time.
- **BE BRAVE:** Ask for help. Support is all around you if you seek it out. You will find that people, like your family, friends, social worker, nurses, technicians and doctor, are glad to help if you ask.
- **BE POSITIVE:** Look at things as half full instead of half empty. Maintain a positive attitude and it will help keep you going.
- **BE YOURSELF:** Nobody is perfect. Do what you think is best for you. Taking care of your health means a healthier and happier life.

Dealing with kidney failure in daily life has helped me find inner strength I didn't realize I had. Once you start taking charge of your health and treatment you'll be amazed to find that you are much stronger than you think. You'll find your way to overcome your own challenges, and you can live a happy and fulfilling life in spite of having a chronic illness.



### Please enter our Naming Contest

(details on back page)

The winning entry will be awarded  
the **Grand Prize of \$100!**



# 2010 Patient Complaints

The Network #15 Patient Services Department recently completed a review of all patient complaints received during 2010. The top 5 complaint areas for patients were:

**Care Coordination**  
**Safety**  
**Respect & Dignity**

**Patient Scheduling**  
**Staff Competency**

As a patient, you have rights and responsibilities and facilities have the responsibility to follow federal and state regulations about the care they provide to patients. It is very important to speak up when you have questions or concerns about your care. The social worker, head nurse, manager and doctor are usually the best people at the dialysis center to talk to about a problem. If you are uncomfortable talking directly to the dialysis center or you aren't happy with the response to your concern about the care you are receiving, we will work closely with you and the dialysis center to resolve the issue. Your state health department is also available to investigate patient complaints about quality of care. Contact information for Network #15 and the state health departments are listed below.

## ESRD NETWORK #15

165 South Union Blvd., #466  
Lakewood, CO 80228  
Toll Free: **1 (800) 783-8818**  
Email: [info@nw15.esrd.net](mailto:info@nw15.esrd.net)

## STATE HEALTH DEPARTMENTS

AZ: **(602) 364-3030**  
CO: **(303) 692-2904** or **1 (800) 886-7689**  
NV: **1 (800) 225-3414**  
NM: **(505) 476-9027** or **1 (800) 752-8649**  
UT: **(801) 538-6158** or **1 (800) 662-4157**  
WY: **(307) 777-7123**

**Three things YOU can do to get more out of your dialysis experience are:**

**Be involved in your care.**

**Know your rights and responsibilities as a dialysis patient.**

**Speak up when you have a question or concern about your care.**

## Dialysis Facility Compare

Medicare's Dialysis Facility Compare (DFC) website puts information about dialysis centers across the country at your fingertips. DFC allows you to search for dialysis facilities by city, county, zip code, or state and provides information on:

- Facility address and phone number
- Types of dialysis offered
- Whether dialysis shifts are offered after 5 pm
- Number of treatment stations
- Percent of patients with adequate hemodialysis
- Percent of patients with anemia under control
- How to compare information among different facilities

Don't know the right questions to ask when searching for a dialysis center? A section called "Patient Tools" provides suggestions on what to ask dialysis care providers and dialysis centers. There are also links to other websites, publications available for downloading, a glossary of terms, a list of useful contacts, and a kidney disease dictionary. To access the DFC website, go to [www.medicare.gov/Dialysis/home.asp](http://www.medicare.gov/Dialysis/home.asp).



## Rewards of Being Involved in Your Care

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

BETTERHEALTH  
CONFIDENCE  
CONTROL  
EMPOWERMENT  
KNOWLEDGE  
QUALITYOFLIFE  
RECOGNITION  
SATISFACTION



*Make note of our  
toll-free number:  
**1 (800) 783-8818***



## Asking Questions: Learning about Dialysis

*By Carol Joyce, Nevada Member  
Network #15 Patient Leadership Committee*

When you first start dialysis it is hard to understand everything that is going on during your treatment. When I first started I didn't want to know anything about it, but as time went by I started asking questions. Questions about different dialysis techniques, what the dialysis staff members were doing to the machine, and how to press the button for the blood pressure. The staff showed me how many kilos I was taking off, and how much time I had left in the treatment. I would also ask what kind of medicine they were giving me through the machine and what it was for. Sometimes I would have to ask several times because I would forget, but the staff would usually tell me again. The next thing I learned is the blood pressure button. I like to take my blood pressure

myself at the end of the treatment so it will free up the nurses and techs for the other patients who need more help. After taking my blood pressure I would also get my weight. I learned everything I could--even about my arm. Now I know so much about my arm that I can show the nurses and techs where to put the needles and how to put them in. I am not a big fan of putting the needles in myself, because my hands shake, so I just let the professionals do it. I have made choices about what's best for me, not what's best for anyone else. It will be different for everyone, but it's important for all of us to ask questions and learn as much as we can.

# Naming Contest - Win the Grand Prize of \$100!

We need a name for our new recorded message line. It's under construction right now and will soon be in operation. It's a Network #15 toll-free phone number that will have recorded messages about topics of interest to dialysis and transplant patients, recorded by **patients!** We can't keep calling it "The Recorded Message Line," so we're hoping that you can help us out. Something short and snappy is what we're looking for. We will review all entries and will pick the one we think is best for the Grand Prize. We have one name in mind already, but if you can suggest something better, we'll use it to rename "The Recorded Message Line." All entries should be in English and must be submitted by **June 1, 2011**. Please fax or mail this entry form. Limit one suggestion per entry, one entry per patient, please:

## RECORDED MESSAGE LINE NAMING CONTEST

My suggestion is: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Dialysis Facility Name/City, State/Phone: \_\_\_\_\_

Mail entries to: **Naming Contest, ESRD Network #15, 165 S. Union Blvd., Suite 466, Lakewood, CO 80228 OR fax to 303-860-8392.**

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## CHECK OUT WHAT'S ON OUR WEB SITE at [www.esrdnet15.org](http://www.esrdnet15.org)

We have a lot of helpful information for patients on our web site about treatment options, including home dialysis and transplant, vascular access information for hemodialysis patients, patient rights, emergency preparedness, Dialysis Facility Compare, and many resources in both English and Spanish! There are also links to other web sites of interest to patients, such as the American Association of Kidney Patients (AAKP), Renal Support Network (RSN), National Kidney Foundation (NKF), Medicare, and the Social Security Administration. **Have a look!**

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