

CONSUMER NEWS

For Northwest Renal Network (ESRD Network 16)
Patients, Family & Friends

4702 42nd Ave. SW
Seattle, WA 98116
(206) 923-0714
Fax: (206) 923-0716

Alaska Idaho Montana
Oregon Washington
Winter 2006



Important Immunizations

When people develop kidney disease, their immune system becomes weak. It is especially important for people with kidney disease to get two vaccinations: the influenza vaccine and the pneumococcal vaccine.

Influenza (flu)

Influenza, commonly called the flu, is a contagious respiratory illness that can cause fever, sore throat, headache, dry cough and muscle aches.

Your annual flu shot, in addition to frequent hand washing, avoiding large crowds and people with the flu, are your best protection from getting the flu.

Pneumococcal (pneumonia)

Pneumococcal infections include many different types of pneumonia. These illnesses can be serious health threats, especially if you have chronic kidney disease.

People only need one pneumococcal shot unless they have a chronic disease, like kidney disease. These people will need an additional dose 5 years after their initial shot.

www.cdc.gov/ni/publications/dialysis-guide.pdf

(Source: Centers for Disease Control)

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Dialysis Facility Compare

Trying to find the best place for your dialysis care? A wonderful resource to assist you is *Dialysis Facility Compare*. This government website provides important information and resources for patients and family members who want to learn more about chronic kidney disease and dialysis.

Use this helpful website to compare facilities and decide where to get dialysis.

Please visit Dialysis Facility Compare at:
www.medicare.gov/Dialysis

Patient Advisory Committee (PAC) Coming Soon!

Do you want to participate in an active, goal oriented, advisory group? Do you want to educate the Network about patients' perspectives? For more information about this wonderful opportunity please contact your facility social worker!

Would You Like to Return to Work?

If you have a disability that makes it difficult for you to get or keep a job, and you want to work, your state Division of Vocational Rehabilitation (DVR) can help.

DVR staff will help you get the information you need to make a good decision about:

- What type of job you want
- Steps needed to reach your goal of going to work; and
- Assist you to design and carry out a step-by-step plan to reach your employment goals

To learn more about how to get started, contact your state DVR to set up an appointment. DVR is a statewide resource for people with disabilities. DVR is a state and federally-sponsored program.

DVR works in partnership with communities and businesses to develop employment opportunities for people with disabilities.

Alaska: 800-478-2815 (in-state use only) or 907-465-2814

www.labor.state.ak.us/dvr/disable.htm

Idaho: 208-334-3990

www.vr.idaho.gov

Montana: 877-296-1197 or 406-444-2590

www.dphhs.mt.gov/dsd/index.shtml

Oregon: 877-277-0513 or 503-945-5880

www.oregon.gov/DHS/vr/index.shtml

Washington: 800-637-5627 (V/TTY) or 360-725-3636

www1.dshs.wa.gov/dvr

The Benefits of Volunteering

Volunteering is when you give your time to help another person, group, or cause. There are many possible rewards to those who volunteer. Volunteer activities offer an important way to connect in a world that may otherwise focus on the limitations of people who are on dialysis instead of seeing what they can do, not only for themselves, but also for others.

Volunteering is a way to give back and use your skills and talents. It's a way to learn new things and have a focus other than your healthcare routines. Volunteering can add structure to your daily life and increased activity levels may improve your stamina. In some cases it's possible for a volunteer experience to lead to a paid position.

We Are Here to Help

We will work with you to try to resolve your concerns or grievances, or to facilitate contact between you and your facility or physician. Here is how to reach us:

- Contact the Network's Patient Services Coordinator at 1-800-262-1514 for assistance.
- If you have a formal grievance, we would like you to provide us the information in writing, if possible, after you make your initial contact with us by phone.
- You may designate anyone you choose as your representative, but you must do so in writing to give us permission to speak with them.
- You can withdraw a grievance at any time.
- You are not required to use your facility's grievance procedure before contacting the Network, although it is recommended that you do explore this option.

The Network will:

- Send you a written acknowledgement within 5 days that your complaint has been received.
- Investigate your concern or complaint.
- Let you know if we determine that the problem is not an issue the Network can address, or is more appropriately handled by another agency.
- Conclude our investigation and resolution activities within 90 days of receipt of your inquiry, and provide a written response to you, including results, and options to follow if you are not satisfied.
- Keep your identity confidential throughout the process unless you specifically authorize us to identify you.

The Network **cannot** handle issues dealing with money, payment of bills, or State or Federal licensure or certification of dialysis and transplant facilities.

These are handled by the Centers for Medicare & Medicaid Services (CMS) Regional Office, or State Survey agencies.

For additional information and phone numbers to CMS and State agencies, please visit our website at www.nwrenalnetwork.org and click on the "Grievance Protocol" link, or see the Northwest Renal Network grievance poster located at your dialysis facility.

ARE YOU PREPARED?

Be ready for any emergency! Here are some tips you should follow:

- *Provide your dialysis unit with current telephone numbers for you and a backup family member or friend.*
- *Maintain a **week's** worth of your current medications at all times*
- *Know the emergency preparedness plan of your dialysis unit and any other units near you.*
- *Remain home if it is safe, and wait for your dialysis unit to contact you.*
- *If you must seek other shelter, take a week's worth of your medication, emergency supplies, personal items, blanket and health records or Medic Alert ID information.*
- *Know how to care for your dialysis access.*
- *Know your dietary guidelines for emergency preparedness.*

Also find emergency information on our website www.nwrenalnetwork.org. Go to the "For Patients" link, Emergency Preparedness section.

The National Kidney Foundation has a "Planning for Natural Disasters- A Guide for Kidney Patients" booklet at www.kidney.org.

(Adapted from ESRD Network 4)

Medicare Part D Prescription Drug Coverage

The Medicare Prescription Drug program began on January 1, 2006.

The Benefits

Medicare prescription drug coverage is insurance that covers both brand-name and generic prescription drugs at participating pharmacies in your area. Everyone with Medicare is eligible for this coverage, regardless of income and resources, health status, or current prescription expenses.

The Cost

All plans vary, but Part D can include monthly premiums, an annual deductible, plus co-pays or co-insurance.

If you have limited income and resources, you may be eligible for extra help where Medicare will pay for almost all of your prescription drug costs.

You can apply or get more information about the extra help by calling Social Security at 1-800-772-1213 (TTY 1-800-325-0778) or visiting www.medicare.gov.

The Drugs Covered

The Kidney Medicare Drugs Awareness and Education Initiative updated its Compare Drug Plans packet on **December 6, 2006**.

You can view and print the full packet at www.kidneydrugcoverage.org/choose.htm. This packet includes a summary on how drugs and plans are chosen, search tips, and two charts that allow you to search for what drugs a specific plan covers (by plan) and what plans cover a specific drug (by drug). *Be sure and have a list of all your medications available!*

The Enrollment Process

Select “enroll” and follow the prompts. Have your red, white, and blue Medicare card available.

Cost-Related Terms to Understand

Catastrophic coverage

If your plan has a coverage gap or “donut hole”, coverage starts again after you spend a total pre-determined amount (usually \$3,850) out of pocket.

Co-insurance

A percentage of the price for each drug.

Co-Payments

A fixed price for your medications.

Coverage gap or “donut hole”

After you and the plan spend a predetermined amount in total drug costs, you may have to pay 100 percent of your drug costs until your catastrophic coverage starts.

Deductible

The amount you have to pay for drugs before your prescription drug plan starts to pay for drugs.

Premium

The amount you pay your insurance plan each month.

For questions and assistance please visit www.medicare.gov or call at 1-800-772-1213 or contact the Statewide Health Insurance Benefits Advisors (SHIBA) HelpLine at 1-800-562-6900. Your facility social worker is also an excellent resource.

(Source: Medicare & SHIBA)



What is Your Treatment Modality?

This list of kidney failure treatment options may not all be appropriate for you medically or be offered by your facility. Discuss your options with your doctor and nurse.

Peritoneal Dialysis (PD)

PD is a treatment where a catheter (plastic tube) is placed into your abdomen near your belly button so a special concentration of electrolytes, called dialysate, can be delivered to your peritoneal cavity. Extra water and waste are drawn out of your blood into the dialysate, then drained out through your catheter into a plastic bag. PD is daily and there are two types.

Continuous Ambulatory Peritoneal Dialysis (CAPD)

CAPD consists of a dialysate fill, a dwell in the peritoneal cavity of about four hours, and a drain. This sequence, called an exchange, is repeated several times a day, every day.

Continuous Cycling Peritoneal Dialysis (CCPD)

CCPD involves a machine that is programmed to do exchanges throughout the night. You connect tubing to your catheter before going to sleep and turn the machine on. In the morning you disconnect the tubing from your machine and you repeat this process each night.

Hemodialysis (HD) -- In-center, Home, and Nocturnal Settings

HD requires access to your bloodstream in order to pull blood out and send it through an artificial kidney called a dialyzer. Excess waste and water are removed and then the blood is returned to your bloodstream. The time for this process may vary from patient-to-patient anywhere from 3 to 4 1/2 hours, usually 3 times a week.

Transplantation

A transplant involves receiving a kidney to replace your lost kidney function. A kidney may come from a friend, relative, or someone who has died. The kidney transplant center will run a series of tests, called a workup, to determine your health status. If the center determines you are healthy enough for a transplant, your name will be placed on the "waiting list." If you have a living donor, they will also go through a workup to determine if they can donate to you. You and your approved donor will be scheduled for transplant surgery.

Please ask your kidney doctor, nurse, or social worker for more information about these different choices. It is important that you choose the modality that is right for you!

Home Hemodialysis - A Patient Perspective

Our Community Outreach Coordinator had an opportunity to meet with Mr. Gary Fletchall, a hemodialysis patient excited about starting home hemodialysis. She visited with him and his wife while they were completing their last training session. Mr. Fletchall, 63, was diagnosed with kidney disease approximately two years ago.

Mr. Fletchall stated he chose to begin home dialysis because of the "flexibility" it offered. He often did not feel well in the mornings when he was scheduled for dialysis. He said he sometimes missed or shortened treatments because he was unable to move his dialysis appointment to a later time. He dialyzed 3 times per week.

The training schedule for home dialysis varies from facility to facility, but requires hands-on training for both the patient and helper on dialysis machine setup/take down, routine and emergency procedures, troubleshooting and cannulation (needle insertion). Competency is assessed through return demonstration and test taking. The training begins by discussing the machine and its parts, and moves to the patient and helper working independently in the treatment with oversight by the nurse. The patient learns how to draw their own labs and send them in; and to inject Epogen.

When Mr. Fletchall starts home dialysis, he hopes that it will provide him a schedule that will work better for his needs.



Northwest Renal Network is currently participating in the Fistula First Initiative. Currently, the percentage of patients in our Network with fistulas is 60.7%, which is the highest in the nation! However, there is still work to do in order to meet the Centers for Medicare & Medicaid Services 2009 goal of 66%.

We are encouraging all patients in our Network to learn more about AV Fistulas. If you already have a fistula, we encourage you to talk to other patients about the advantages that you have experienced. Please be aware that not all patients will be able to have a fistula due to small and/or diseased vessels, heart damage, or other health issues. Other types of accesses are listed below.

Vascular Access Types

What type of vascular access do you have for hemodialysis - a catheter, graft or fistula?

CATHETER: can be used immediately, doesn't require needles, and is used when your blood vessels are diseased or your heart has been damaged. However, it frequently becomes infected and/or clots off in a short period of time. If you do develop an infection from a catheter, it usually has to be removed. Sometimes you will have to be hospitalized if the infection is severe enough.

GRAFT: is an artificial piece of material that is connected at one end to a vein and the other end to an artery. The biggest drawback of a graft is clotting because of a narrowing (stenosis) of the blood vessel. When a graft clots you have to see a radiologist or a surgeon and have it cleaned out.

FISTULA: is by far the best access, meaning it lasts the longest, requires the least amount of repair or revision, has the least number of infections, and allows higher blood pump speeds that clean your blood better. Some patients have had their fistulas for 20 - 30 years! Talk with your doctor or your nurse to see if you are a candidate for a fistula.

THE BUTTONHOLE TECHNIQUE

For those patients who have arteriovenous fistulas (AVFs), there is a cannulation (needle insertion) technique that has fewer complications, and less pain than rotating sites, called the Buttonhole Technique.

With this technique, your fistula is cannulated at the same two sites every dialysis, which will cause a tunnel to form that is very similar to a pierced earring hole. Once this tunnel is formed, then you will switch from sharp needles to special blunt (buttonhole) needles. Check with your nurse to see if your facility uses the Buttonhole Technique for fistulas.

You can find more information on the Buttonhole Technique on the Network website at <http://www.nwrenalnetwork.org/fist1st/ButtonholeBrochureForPatients1.pdf> or contact:

Lynda Ball
Quality Improvement Director
Northwest Renal Network
1-800-262-1514
lball@nw16.esrd.net

Welcome Martha Hanthorn, Executive Director

Northwest Renal Network is pleased to introduce Martha Hanthorn, who joined the Network as Executive Director on 3/1/06. She has a strong advocacy and customer service focus in working with chronic kidney disease patients, their support persons, and treatment centers.

Ms. Hanthorn has a Master of Social Work degree and is a Licensed Clinical Social Worker. She has spent her professional career in medical settings, with over 15 years in dialysis programs. She has

worked in the areas of medical and dialysis social work, administration, and management of a home dialysis program. Prior to accepting this position, she was a member of the Network's Medical Review Board for 10 years.

Her knowledge of issues patients and their families face, government regulations and quality care for kidney patients is an asset to the Network. She looks forward to continuing to assist the kidney community in her new role. Welcome!

What is a Network? What Can They Do for Me?

WHO WE ARE

Our mission is to promote optimal dialysis and transplant care for kidney patients in Alaska, Idaho, Montana, Oregon and Washington.

Our goals include improving the quality and safety of care for people receiving treatment for End Stage Renal Disease; improving their independence, rehabilitation and quality of life; and resolving patient grievances. We are funded by a contract with the Centers for Medicare & Medicaid Services, Department of Health and Human Services.

WHAT WE DO

- ◆ **Collect and analyze patient data to monitor quality of care**
- ◆ **Work with dialysis and transplant providers to improve patient outcomes**
- ◆ **Serve as an unbiased third party in responding to concerns or complaints about care at dialysis and transplant programs**
- ◆ **Provide resource information to the chronic kidney disease community**
- ◆ **Work with other agencies and organizations to improve patient outcomes**

Please visit our website or call us on our toll free number below to learn more about the Network grievance process, location and contact information for the Network office, our most current annual report, Network goals, a link to Medicare.gov/DFC, and many more helpful resources, tools and links!

We are on the web!
www.nwrenalnetwork.org
Patient-Only Toll Free Number
1-800-262-1514

STAFF NOTES

A Warm Welcome!

Christie Hurley
**Quality Improvement/
 Community Outreach
 Coordinator**

Christie joined the Network in November 2006. She has a dual Master's degree in social work and public administration. She has experience in a hospital setting and outpatient case management for HIV/AIDS patients.

She is a liaison with the kidney community and other organizations, and she will work closely with patients in creating a Patient Advisory Committee for our Network.

Christie can be reached at churley@nw16.esrd.net or 206-923-0714 ext 102.

Michelle Cummings
**Administrative and
 Project Assistant**

Michelle joined the Network in December 2006. She began her dialysis career in 1994 at a community dialysis center. She will use her prior renal knowledge in this new role to continue learning about ESRD and patient issues.

She is a key person who keeps the office operating smoothly and assists staff with their many projects.

Michelle can be reached at mcummings@nw16.esrd.net or 206-923-0714 ext 101.

A Fond Farewell!

Marylou Pederson
Patient Services Coordinator

"The patients are my heroes". Marylou has been the Patient Services Coordinator for six and a half years. She states that she has mixed emotions about leaving the Network as the position has been interesting, rewarding, challenging and fulfilling. She is excited about moving on to a new adventure, although she will miss her co-workers and wonderful people she has met in the renal community.

She considers it a privilege to have been able to work with patients as they faced challenges and struggles, finding solutions and assisting everyone with the delivery of safe, appropriate care.

Ada McAllister
Administrative Support

"Five wonderful years". Ada will miss her co-workers and all of the people she met and talked to at the dialysis units. Many of you may have spoken with her as she often answered phones at the Network in addition to working on administrative projects.

She states that working for the Network has been a wonderful experience that increased her awareness of health care issues. Ada is looking forward to retirement, but plans to stay up to date on Network activities.