

Renal Outreach

The Renal Network, Inc.
ESRD Networks 4, 9 & 10

**Working to facilitate the
achievement of optimal wellness for
renal disease patients.**

ESRD Network 9 & 10

Medicare D Prescription Drug Coverage Program



All Medicare patients may sign up for the Part D prescription drug benefit made

possible by the Medicare Modernization Act (MMA) of 2003. The federal government formed a partnership with dozens of medical insurance companies in each state to provide the Medicare D prescription drug program. It has helped hundreds of thousands of Americans on Medicare afford prescription drugs.

The Network patient Web site, Kidney Patient News has links to a number of resources that you can download or link to other helpful sites. Just go the Web site (www.kidneypatientnews.org) and click on Medicare Part D link located on the left hand side of the page.

Medicare beneficiaries also may find their Medicare Handbook helpful in choosing prescription drug plans. All beneficiaries receive an updated

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report every year. If you do not have one, you can download it from the link above. In the back of the book is a glossary containing a list of Medicare D prescription drug plans and Medicare supplemental plans for the state in which you live. It includes toll-free telephone numbers, whether or not a plan has a deductible, co-pay amount per prescription, and ways to compare prescription drug plans to find the best one for you.

ESRD Networks 4, 9 & 10 Merge Under The Renal Network, Inc.

ESRD Network 4, ESRD Network 9, and ESRD Network 10, which monitor quality of dialysis care, have merged under The Renal Network, Inc., a not-for-profit corporation which has been the contract holder for ESRD Network 9 and Network 10 since 1996.

The role of The Renal Network continues to be to promote and support quality dialysis care and outcomes of ESRD patients and kidney

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transplant patients through patient services, education, quality improvement and the collection, analysis and exchange of relevant incidence, prevalence, surveillance and outcome data. This merger creates a six-state regional network area covering Pennsylvania and Delaware (Network 4); Indiana, Ohio and Kentucky (Network 9); and Illinois (Network 10).

The merged networks of The Renal Network now serve approximately 58,537 patients in 989 dialysis facilities, and 42 kidney transplant centers. ESRD Network 9 and ESRD Network 10 will remain headquartered in Indianapolis, Indiana, and the ESRD Network 4 office will remain in Pittsburgh, Pennsylvania. The staffs at both Networks remain the same.

You will now see a new logo on all Network resources but you may continue to use the Network 9 & 10 toll-free number 800-456-6919 to reach the Network office in Indianapolis.

Transplant Resources

To access to U.S. government information on organ and tissue donation and transplantation visit **www.OrganDonor.gov**. This site provides information on being a donor, transplantation basics, how to reduce the risk for needing a transplant, and information on research, best practices, and legislation. www.organdonor.gov/get_involved/donatelifemonth.htm

American Association for Kidney Patients (AAKP)

Kidney Transplant Today is a newsletter devoted to those interested in learning about transplantation or those who have received a kidney transplant. www.aakp.org/newsletters/Kidney-Transplant/

Kidney Patient News

This site provides resources for potential transplant patients and information about other resources. www.kidneypatientnews.org/treatment/transplant.php

Dialysis Facility Compare

Did you know that there is a Web site that will give you information about Medicare-certified dialysis facilities?

Did you know that you can use this information to help you choose a dialysis facility?

The Web site is called Dialysis Facility Compare: **www.medicare.gov/dialysis**.

Dialysis Facility Compare (DFC) provides information as well as quality measures, for each facility. You will learn which facilities have shifts starting after 5:00 pm, the number of their treatment stations, the type of dialysis they offer, and whether or not they are profit or non-profit and corporately owned or independently owned.

Complaints and Grievances

During 2009, The Renal Network, Inc. received 107 complaints primarily from patients and family members and there were two grievances filed at the Network level. The complaints were primarily related to two areas – quality of care and staff-related concerns.

There were 62 patients involuntarily discharged from facilities primarily for disruptive, threatening and abusive behaviors and many of them were also non-compliant to treatment. Of the 40 patients who were having a difficult time finding placement in a facility, over half of them were described as having behavior-related concerns, primarily non-compliant to treatment and verbally abusive. More information about the Network trends is on our Web site at www.therenalnetwork.org/data/grievance.php.

When you have a complaint about your care or your patient care provider, the Network encourages you to talk to your staff to resolve the issue. You also can file a written complaint at your facility. Ask your staff for a copy of the *Facility Complaint and Grievance Process* and follow the steps listed. Provide as much information about your concern as possible and meet with the staff to find a solution.

If you are not satisfied with how your facility handled your complaint, or you do not want to go through your facility

first, you may contact The Renal Network for assistance with your complaint or grievance.

The Network can help you solve your complaint by providing suggestions on how to work with the staff, can contact the facility with your permission to investigate your concern and intervene on your behalf, can provide other agency resources that may be of assistance.

More information about the Network's complaint and grievance process can be found on our Web site at www.therenalnetwork.org/about/grievance.php.

Kidney Transplant Medication — Part II

Other Commonly Prescribed Non-Immunosuppressive Medications



By Dadi Ding, RN, Renal Transplant Coordinator of Loyola University Transplant Program and member of The Renal Network Patient Leadership Committee

In addition to anti-rejection medications, a few other types of medications are

prescribed for you after kidney transplantation.

A. Anti-viral drug:

Valcyte (Valganciclovir):

This medication is used for preventing illness caused by a virus called Cytomagalovirus, which is usually referred to as CMV. CMV infection in a person with a normal immune system is very mild and often causes no symptoms or just mild flu-like symptoms. Between 50-80% of adults in the United States are infected with CMV by 40 years of age and have antibodies against the virus.

Once CMV is in a person's body, it stays there for life. After transplantation, you are given medications to suppress your immune system to prevent rejection. Your weakened immune system provides a good environment for the virus to multiply, which may cause severe disease.

You may be infected for the first time at the time of your transplant if your donor has it and you never developed antibodies against it before your transplant, or you may experience reactivation of the dormant or inactive virus you already harbor in your body from previous infection before your transplant. Either situation can lead to severe or even life-threatening illness if not recognized and treated early.

CMV disease can be present in various ways, such as pneumonia, stomach or intestinal infection, or severe flu with fever and chills. It can also result in worsening kidney function. It is a common practice now in the U.S. for post-transplant patients to receive Valcyte for three months if there was pre-transplant CMV infection, or six months if the patient never had it before and the donor tested positive for CMV antibody.

B. Antibiotic:

Bactrim (Sulfamethoxazole/Trimethoprim):

This is an antibiotic often used to treat urinary tract infections. After your kidney transplant, you will be placed on this medication for one year to prevent a rare lung infection called Pneumocystis pneumonia, or PCP.

It is a pneumonia caused by a yeast-like fungus called Pneumocystis carinii, often seen among immunocompromised patients, such as AIDS patients or transplant patients.

In order to prevent this infection in transplant patients, the majority of the transplant centers in the U.S. place patients on this medication for one year after transplantation.

C. Anti-fungal medication:

Nystatin: This is an oral suspension taken by swishing and swallowing after each meal and at bedtime to prevent

fungal infection in the mouth in immunosuppressed patients, usually for three months post-transplant.

D. Antacids:

There are many drugs in this category such as Zantac, Pepcid, Protonix, Nexium, Prevacid and Aciphex.



It is the transplant center's preference to choose one of these drugs to prevent or treat acid reflux among

post-transplant patients, typically for the first few months after the transplant, when they are on higher doses of Prednisone, which can cause stomach irritation and ulcers.

Later in the course, antacids can be used as needed to treat acid reflux. Most of these medications you only need to take for a short period of time. In most cases, three months after the transplant, your medication list becomes much shorter.

There are other medications you may need for control of high blood pressure, high cholesterol or high blood sugar, for a heart condition, or for other medical problems you may have. These are individualized for each patient.

This article as well as four other articles related to transplantation can be found in the booklet, *After Your Kidney Transplant*, a new Network resource.

Employment Support through the Social Security Programs

The Social Security Administration (SSA) wants to support disabled beneficiaries in their efforts to work by having work incentives. Its *2010 Red Book: A Guide to Work Incentives* can be a self-help guide to you in understanding the SSA disability-related policies.

Your social worker probably has a copy of the book and can also assist you in understanding “employment supports” that help you enter, re-enter, or stay in the workforce by protecting your eligibility for cash payments and/or health care until you achieve your goals for benefit independence.

The *Red Book* gives you such information as what is new for 2010, the resources for employment supports, return to work planning and assistance, and your responsibilities when you return to work.

You can get more information by going to www.socialsecurity.gov, calling the SSA toll-free number at 800-772-1213 or you can fax your requests for public information materials, including the *Red Book* to 410-965-2037.

You also can view the entire Red Book online or download in PDF format from at www.socialsecurity.gov/redbook/.

Winners of *The Robert Felter Memorial Award*

In March of 2002, The Renal Network, Inc. ESRD Network 9 & 10 announced the creation of *The Robert Felter Memorial Award* in honor of the late Bob Felter, a kidney patient, educator, leader and a spokesperson for dialysis and transplant patients. The award honors applicants who have successfully adjusted to living with kidney disease, and who have actively worked on behalf of other patients.

The Robert Felter Award applications are evaluated by several members of The Renal Network staff and members of the Patient Leadership Committee with one winner selected from each Network. The winners are presented with an expense paid trip to a renal conference. Following the conference, winners are asked to write an article sharing what they have learned and enjoyed while attending the conference.

The Renal Network is pleased to announce that **Diana L. Belton**, Network 9, and **Lana Schmidt**, Network 10 are the 2010 Robert Felter Memorial Award winners.

We would like to introduce you to these special patients who have successfully learned to cope with their illness, and to share how they have reached out to patients, family members, and health care providers and others in their community. Along with their work with the renal population, the winners have

volunteered in their churches and in the community.

Diana L. Belton lives and works in Akron, Ohio. She is a dialysis patient at Diversified Specialty Institutes (DSI) as well as a full-time administrative assistant at her facility for the past ten years.

She is a member of the Summit City Kidney Foundation Board and a member of the American Association for Kidney Patients. Diana has been a patient advocate for legislation on Capitol Hill.

As a community and church volunteer, Diana chaired a committee to feed the homeless, volunteered with the battered women's program, and she has worked as a youth advisor for 15 years. Diana served with the missionary department to build a school in Haiti.

Diana has accepted the changes in her life since being diagnosed with chronic kidney disease. She has coped with the need to depend on others to care for her, and that no matter how hard she tries some things are simply out of her control. Diana has realized that she has limitations in her daily life, but these limitations do not define her.

Lana Schmidt, Network 10's winning applicant and a patient at Davita-Blessing Hospital, currently lives in Liberty, Illinois. Lana uses her in marketing skills and experience to obtain media coverage to promote kidney disease awareness.

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She created a Christian CD “*Healing Waters*” to help her and others living with kidney disease.

While residing in New Zealand, Lana Schmidt established the Kidney Patient Network Support Group.

She also developed the Web site **www.Kidneypatientnetwork.Wellington.net.nz** and organized a 400K Kidney Walk with 20 corporate sponsors.

The social worker at Lana’s facility wrote in her letter of recommendation that “Lana is a dynamic person who happens to need dialysis. She always wears a smile and carries a word of encouragement for all those around her. Lana is passionate about getting knowledge out about kidney disease to the public.”

The Renal Network was extremely pleased with the applications that were received from both Network 9 & 10 for this year’s award. Although it was difficult to select only candidate from each Network, it was heartwarming to learn that so many of the applicants are successfully managing their disease, and that they have reached out to others at their dialysis units, and they provided their insight to health care staff, the media and individuals in their community.

We congratulate the winners and all of the applicants.

Hand Hygiene is Important

Hands Collect Germs

Hands are the most exposed part of the body to germs. Your hands can collect all kinds of germs when doing everyday things like using the telephone, opening doors, or handling money. Germs are easily transferred into the body by your hands when touching the eyes, mouth, nose or food.

Germs are everywhere but can be found in some places more than others. Some common areas where germs can hide are:

- Doorknob
- Garbage can
- Computer keyboard
- Handrails
- Shopping cart handles
- Light switches
- Remote controls
- Pens and pencils

Diseases and Hand Washing

Some diseases are caused by germs, some are not. Germs that your hands collect can be spread to other surfaces that you touch. Simply washing your hands can help prevent such illnesses as the common cold or flu from spreading to you and to others.

RENAL OUTREACH

Address Service Requested

The Renal Network, Inc
911 E. 86th Street, Suite 202
Indianapolis, IN 46240
Phone: 317-257-8265
Patient line: 800-456-6919

George Aronoff, M.D., President

Susan A. Stark, Executive Director

Kathi Niccum, Ed.D., Editor
Patient Services Director

Patient Web site: www.kidneypatientnews.org

Email: info@nw10.esrd.net

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Hand washing is an essential part of vascular access care and helps to prevent infection to the access site.

Although particular attention is paid to hand hygiene before dialysis, it also is important to be mindful of hand hygiene even when not at dialysis.

Your dialysis access is your lifeline. Take time to learn about it and care for it. A little effort can make a big difference.

Hand Washing Techniques

There are six basic steps to washing your hands:

1. Wet hands with warm, running water.
2. Add soap.
3. Rub hands vigorously for 20 seconds and wash all surfaces including:

- Backs of hands
- Wrists
- Between fingers
- Tips of fingers
- Thumbs
- Under fingernails (use nailbrush)

4. Rinse. (keep fingers pointing down)
5. Dry vigorously with paper or clean cloth towel.
6. Turn off faucet with towel and open door with towel.



**Clean
Hands
Save
Lives!**