

ESRD NETWORK 13

4200 Perimeter Center Drive, Ste 102
Oklahoma City, OK 73112-2314
(405) 942-6000
www.network13.org

**KIDNEY
CONCERNS****SUMMER/JULY 2006****ISSUE 56****Lessons Learned: Even the Best Intentions****By: Jerry Chambers**

I have been a Hemodialysis (HD) patient for 7 years. I went into renal failure due to extremely high levels of hypertension; a condition I have had since the age of 13 along with diabetes. Being a third generation dialysis patient, the procedure was not new to me. On the advice of a trusted and time-honored friend in the medical profession, I moved to Louisiana to join the transplant list. With the aid of this medical professional, I was on the list in no time and under this friend's personal nephrology care.

I soon received a double organ transplant, kidney and pancreas, and I was elated! My general health improved greatly, including my failing eyesight. The transplant surgeons were ecstatic with the ease in which I adapted to memorizing the diet and many medications. They released me to the care of my local physician who continued to provide nephrology care during my rehabilitation period. I viewed the world through renewed bright-eyed optimism and decided to go back to college to work on my degree in Literature.

It was not long before problems ensued that my nephrology doctor was not equipped to handle so he sent me back to the transplant team. Over the next 15 months this would be the procedure more than 7 times which inspired concern as to whether my healthcare was being mismanaged. Due to what was later established as toxic shock caused by over medicating, I lost my transplanted organs.

It is not often that one has a close friend in the medical profession that can provide aid and outlets for one's advancement, but it was a costly lesson for me to learn that finding the right doctor is essential in your well-being. Friendship is wonderful if it can be established between physician and patient but you have to know where to draw the line when your healthcare needs are not being met. I encourage every patient to be informed about their own healthcare and the credentials of their healthcare providers. My life has been altered because I did not want to cause a rift between friends and it is my health that is paying the price. ●

MedlinePlus® Adds Tutorial on Evaluating Internet Health Information**By: National Library of Medicine**

As consumer health information Web sites explode on the Internet, teaching people how to evaluate information for accuracy and authority becomes more and more important. With this in mind, MedlinePlus now features a tutorial on the topic.

Evaluating Internet Health Information (<http://www.nlm.nih.gov/medlineplus/webeval/webeval.html>) is a 16-minute narrated slideshow. The tutorial runs automatically, but you can use the navigation bar at the bottom of the screen to go forward, backward, pause, or start over. Using fictional "good" and "bad" Web sites, the tutorial walks the user through a comparison of the two, pointing out features to look for concerning the information provider, funding source, quality, and privacy. The tutorial uses plain language and narration and is appropriate for users at a broad range of reading levels. ●

**Your Opinion Counts, Look For Kidney Concerns Evaluation on Page 7
Complete and Mail to the Network 13.**

Educate Yourself!

By: Heather Powell, Network 13 PAC Member

“Knowledge is power” as the saying goes and that stands true for living with a chronic illness. The more you know, the more informed choices you can make. The more informed your choices, the more control you have in making good decisions. We must be careful where we get our information. Always consult your doctor before relying on information you received via the web, print or word of mouth when making a decision about your health. Make sure your information is coming from a credible, reliable source and that the content is accurate and valid. Things to look for (or be wary of) when gathering information:

- ◆ Offers a quick fix? There are no quick fixes. If the site offers information on an herb, medicine, exercise, or treatment as a cure; beware. What are they promoting?
- ◆ Selling something to help or heal Chronic Kidney Disease. Don't purchase anything without consulting your doctor first.
- ◆ Where's the information coming from? Who's behind it? Is it connected to a company or particular industry? The information may be good but understand there might be other options not listed or discussed.
- ◆ Is it clear and concise, easy to understand, backed up with references and/or research? It should be verifiable and good information will be repeated.
- ◆ Just the facts. If the person or source has biased or negative information about a specific treatment, person, facility, etc, beware of the content.

Another saying is “a little knowledge is a dangerous thing”. This stands true as well. We can have limited knowledge on a topic and make a very bad decision. The best thing is to gather good information on the topics that interest you. Read over all the information and come up with questions and concerns to address with your doctor. Being knowledgeable about our disease can empower us. It can help us feel more ‘in control’ in an ‘out of control’ situation. Bad information can be destructive. When applied to your health it can even be deadly.

You may be feeling overwhelmed. You may be unsure where to even start on your journey of knowledge. Ask questions, talk to other patients and medical professionals, request literature and brochures. Where can you go to get information about your diagnosis?

Some of my personal favorite websites that have good information on kidney disease, treatment options, nutrition, coping, etc. are:

- 1- Kidney School: www.kidneyschool.org (internet learning modules on kidney topics)

- 2- National Kidney and Urologic Diseases Information Clearinghouse: <http://kidney.niddk.nih.gov> (information on urology, diabetes, kidney disease, etc...).
- 3- National Kidney Foundation: www.kidney.org (general public, at risk, and kidney patient information available).
- 4- Renal Support Network: www.rsnhope.org (patient focused & run, current legislative issues of interest to kidney patients).
- 5- End Stage Renal Disease Network 13: www.network13.org (public, patient, and caregiver information; quality of care & grievance issues).

You can surf the web at your local library or check with your local NKF affiliate. I advise newly-diagnosed patients to start with the kidney school website. To have something in hand, order free brochures through the National Kidney and Urologic Diseases Information Clearinghouse Web site. If you want to connect with another patient, go to the Renal Support Network website and look for a bridge member in your community. Your clinic may have a patient educator that you can talk to as well. It is good to utilize every available resource to find information. Remember, knowledge is powerful! ◆

RSN's “Kidney Talk!” Hit The Airwaves in June

RSN Press Release

Making its debut on June 6, KidneyTalk!—an online radio talk show developed by the Renal Support Network (RSN) for the renal community—began streaming “health, happiness, and hope” over the Internet.

The co-hosts of this weekly, half-hour show will be RSN President & Founder, **Lori Hartwell**, and **Stephen Furst**, an accomplished television and movie actor/producer/director recently diagnosed with end-stage renal failure and now on dialysis. Furst is best known for his roles as Flounder in the movie “Animal House,” Dr. Elliot Axelrod in the TV series “St. Elsewhere,” and Vir Cotto in the TV series “Babylon 5.” Also a diabetic, Furst is the author of the award-winning book Confessions of a Couch Potato (Or, If I'm So Skinny, Why Do I Still Feel Like Flounder?), published by the American Diabetes Association, for which he is a spokesperson.

Every Tuesday at 2:00 p.m. Pacific time, a new show will be uploaded to the KidneyTalk! webpage—located on the RSN website, RSNhope.org—and will also be accessible as a podcast. Each show will be available online 24 hours a day, seven days a week; past shows will be archived on the webpage as well.

With Hartwell's 37 years as a renal disease survivor and Furst's entertainment credentials, KidneyTalk! will provide practical advice on living a productive life despite chronic kidney disease (CKD), and will do so in an informal and entertaining format. ◆

25 Years and Going Strong

By: Sharon Waggoner, LCSW, FMCNA West Shreveport

Surprise and celebration were the order of the day at a party honoring Mr. Tony Scott, a dialysis patient at FMCNA West Shreveport. Mr. Scott has been on dialysis for 25 years as of May 1, 2006. The clinic manager, Lindy Richards, RN, and her staff at FMC West Shreveport orchestrated a surprise celebration complete with decorations, food and cake on his silver anniversary date.

Mr. Scott began dialysis on May 1, 1981, at the age of 24 years old. He believes he received lead poisoning from painting a house, which caused his kidney failure. He said, "there were no free standing dialysis facilities in the area at the time and I received my treatments at a hospital-based facility." He later began dialyzing at the first freestanding outpatient facility, FMCNA Shreveport, when it opened. Tony recalled, "the social worker came and told all of us who were not bedridden that we would have to go." He also remembers being hooked up to the machine directly through two needles in his wrist, one in the vein and the other in the artery. He attributes his longevity to his strong faith in God and always trying to stick close to the guidelines he is educated about. "If they told me I was not supposed to eat something, I didn't eat much of it", but he states, "if it was not for my Lord and Savior Jesus Christ, I would not have come this far."

When asked how he overcame the anguish and despair that sometimes comes with being diagnosed with kidney failure, especially as a young man, he explained that although he did have some of those feelings and did not think he could live this lifestyle, "I later came to my senses. I looked at it like getting up every morning going to a job, to do what I needed to do to survive."

Tony fondly remembers, "I have met some beautiful people in dialysis, nurses and techs, and have been encouraged by lots of them, and I also encouraged lots of them as they trained on the job."

As you can tell, Mr. Scott is an inspiration to everyone around him. He is a kind-hearted and positive person while being a model patient. He is a joy to all to have as a patient at the facility. His final thoughts on his journey with kidney disease, "I trust in the Lord and depend on him to supply my every need, and that's how I made it, that's how I'm making it now, and that's how I will always make it." ◆

SEND US YOUR STORY

The *Kidney Concerns* is interested in hearing from you. If you or someone at your facility has overcome adversity, reached a milestone, been successful in starting a hobby, returned to work, volunteerism, made healthy lifestyle changes, started a support group or other activities that has improved your quality of life, we want to hear about it so we can share it with the patient population of Network 13. Your story may be the motivation another patient needs to take that first step towards success. Submit your stories by fax at **405.942.6884** or mail to:

Kidney Concerns
4200 Perimeter Center Drive Suite 102
Oklahoma City OK 73112-2314

UPCOMING NATIONAL AND NETWORK PATIENT CONFERENCES

Increase your knowledge, meet others, share your experiences. Attend a patient conference and/or meeting

National:

- AAKP 33rd Annual Convention
- August 31-September 3, 2006
- Renaissance Orlando Resort at Seas World
- Orlando FL
- Contact: www.aakp.org or call 800.749.2257 for Information

- Renal Support Network
- October 5- October 7, 2006
- Philadelphia Marriott
- Philadelphia PA
- Contact: www.RSNhope.org or (818) 543-0896

Network 13 Patient Meetings:

- ESRD Network 13 Arkansas Patient Meeting
- 6PM - 9PM
- September 25, 2006
- Embassy Suites Little Rock
- **Little Rock AR**
- Contact: 800.472.8664

- ESRD Network 13 Oklahoma Patient Meeting
- 6PM - 9PM
- October 11, 2006
- Oklahoma City Marriott
- **Oklahoma City OK**
- Contact: 800.472.8664

- ESRD Network 13 Louisiana Patient Meeting
- 6PM - 9PM
- October 23, 2006
- Holiday Inn Select Baton Rouge
- **Baton Rouge LA**
- Contact: 800.472.8664

Cool 'n' Crunchy Chicken Salad

By: Susan Knapp, MS RD LD,
Network 13 Medical Review Board
Recipe from <http://davita.com>

Top Ten Fluid Tips

By: Susan Knapp, MS RD LD,
Network 13 Medical Review Board

Summertime can be an especially difficult time to control fluids. Here are a few tips that may be helpful.

1. **Drink from small cups.**
2. **Ice cold drinks quench thirst better than hot drinks.**
3. **Suck on ice cubes or a sugar-free Popsicle.**
4. **Chew on gum or suck on hard candy (sugar-free if diabetic).**
5. **Rinse your mouth out with chilled mouthwash.**
6. **Suck on a frozen lemon wedge or eat frozen grapes.**
7. **If diabetic, control blood sugars to decrease thirst.**
8. **Measure your fluid intake every day.**
9. **Postpone drinking. You are usually most thirsty following dialysis.**
10. **Limit sodium & avoid salty foods to decrease thirst.**

Medicare Announces Special Election Period for Low-Income Beneficiaries and Those Affected by Katrina

The Centers for Medicare & Medicaid Services (CMS) announced a demonstration program allowing certain Medicare beneficiaries to enroll in a Medicare prescription drug plan with no penalty through December 31, 2006. The program is available for seniors and people with a disability who qualify for the extra help for their Medicare prescription drug coverage, or who live in an area affected by Hurricane Katrina. People who qualify for extra help account for the vast majority of Medicare beneficiaries who have not yet enrolled in Medicare Part D or do not have other "creditable" coverage.

Eligible Beneficiaries

Late enrollment penalties will not be collected for certain beneficiaries who enroll in a prescription drug plan under the new Special Enrollment Period:

1. **Individuals who enroll in the low-income subsidy; and**
2. **Individuals who were affected by Hurricane Katrina**

Individuals who apply and are approved for the low-income subsidy experience a significant change in status, in particular, they become eligible for very comprehensive drug coverage at low or no cost. With this change in status, they have a special enrollment opportunity to enroll in a prescription drug plan any time throughout 2006. If they do not enroll in a plan on their own, Medicare will facilitate their enrollment into a prescription drug plan with a premium below the low-income benchmark, but they will have the opportunity to change plans before December 31, 2006.

Servings	6 portions
Serving size	1/2 cup
Ingredients	<ul style="list-style-type: none"> • 2 cups cooked chicken, diced or shredded • 1 large hard boiled egg, chopped • 2 tablespoons onion, diced • 1/4 cup celery, diced • 1/4 cup low-fat mayonnaise • 1 teaspoon fresh lemon juice • 1/3 teaspoon sugar • black pepper to taste
Preparation	<ol style="list-style-type: none"> 1. Dice or shred chicken. 2. Chop egg, onion and celery. Place in a large bowl. 3. Add mayonnaise, lemon juice, sugar and black pepper. Stir all ingredients together. 4. Cover and chill overnight or at least 2 hours before serving. 5. If desired, serve on bread, roll, croissant or pita bread with green leaf lettuce.
Nutrients per serving	<ul style="list-style-type: none"> • Calories: 127 • Protein: 16 g • Carbohydrates: 2 g • Fat: 6 g (1 g saturated fat) • Cholesterol: 75 g • Sodium: 95 mg • Potassium: 136 mg • Phosphorus: 122 mg • Calcium: 14 mg • Fiber: .2 mg
Renal and Renal Diabetic Food Choices	<ul style="list-style-type: none"> • 2 meat • 1 fat



Individuals who are affected by Hurricane Katrina will be considered eligible for this demonstration if, at the time of the Hurricane (August 2005), they resided in any of the parishes or counties declared as meeting the level of "individual assistance" by the Federal Emergency Management Agency (FEMA). FEMA has identified the parishes and counties declared eligible for "individual assistance" as a result of Hurricane Katrina and can be found at www.fema.gov/news/disasters.fema?year=2005.

Timing/Duration

The demonstration program is limited to beneficiaries who enroll beginning in June, 2006 through December, 2006. As long as they stay continuously enrolled in a Part D plan, they will not be assessed a late enrollment penalty. If they disenroll after 2006 and do not have creditable coverage for a continuous period of 63 days or more, they would then incur a late enrollment penalty when they re-enroll in a plan. ◆

Treatment Options

By: Heather Powell, Network 13 PAC Member

There are no cures for kidney disease, **yet!** But, your life doesn't end with a diagnosis of kidney disease. There are treatment options available: hemodialysis, peritoneal dialysis, and/or transplantation.

Hemodialysis (HD) can be done in a clinic or at home. Hemodialysis uses needles to carry blood from your body into a machine that filters the blood, removes excess fluid, and returns it to your body. It's generally done in a clinic setting, but some people do home-hemodialysis. If you choose in-center hemodialysis, you will travel to a clinic 3 times a week for your treatments. Home-hemodialysis takes major dedication, determination and a helper. But it can be done. I have personal experience with home-hemodialysis and for me it was a great option. If you are interested in home-hemodialysis, check to see if your dialysis facility offers it as an option. It may be that they don't. If that is the case and you still wish to pursue home-hemodialysis, check the Dialysis Facility Compare Web site www.medicare.gov and see if there is a clinic in your area that offers home-hemodialysis.

Peritoneal dialysis (PD) is done at home. PD uses your peritoneal membrane as the filter. A tube is placed in your stomach. Fluid is put into the peritoneal cavity through the tube in your stomach, where it uses diffusion and osmosis to remove excess fluid and filter the blood. The fluid is drained out. You can do this several times a day (called exchanges), which is called CAPD or Continuous Ambulatory Peritoneal Dialysis or you can use a machine at night while you sleep to do exchanges, called CCPD or Continuous Cycler Peritoneal Dialysis. Which type you do is determined on your body type and what works best.

Transplantation is the third option. A kidney from someone else is surgically placed in you. Your family can be tested to see if they can donate to you, or you can be placed on the waiting list for a cadaveric transplant, which is from someone who has passed away. If you are interested in pursuing a kidney transplant you will need your nephrologist to make a referral to a transplant doctor. This doctor will give you information about transplantation and do a work-up to see if this is a viable option for you. All three are good options; you must decide which is best for you. Some treatments work better for some individuals. It is good to discuss each option with your doctor. It might help you to make a list of pros and cons about each option to better make a decision. The more you know about your disease, the better decisions about your health care you can make.

If you are interested in any of the options listed here, you can get more information at the following Web sites:

Kidney School: www.kidneyschool.org

National Kidney & Urologic Diseases Information Clearinghouse: <http://kidney.niddk.nih.gov>

National Kidney Foundation: www.kidney.org

If you have recently been diagnosed with chronic kidney disease, just remember that there is always hope. ◆

Study Identifies Barriers to Kidney Donations

U.S. Newswire/ Copyright 2006, U.S. Newswire

Pre-existing medical conditions, financial concerns and a reluctance to ask family and friends to be donors constitute the most significant barriers to live kidney donations among African-Americans, according to a study in the June issue of the Journal of the National Medical Association (JNMA).

Prabhakar Baliga, M.D., the lead author and a Transplant Surgeon of medicine at the Medical University of South Carolina, conducted focus groups of 18 health care providers in South Carolina and he said, "Other barriers included a distrust of the medical community, fear of surgical procedures and lack of awareness of living donor transplantation programs".

The study underscores racial disparities that continue to interfere with many areas of health care, including kidney transplants. In South Carolina, for example, African-Americans made up 68 percent of the waiting list for kidney transplants from 1988 to May 2005. They received 49 percent of the transplants during that time. In addition, only 20.8 percent of kidney transplants came from living donors, only one-third of which were African-Americans. "This study is one of only a few that explored perceived barriers to living kidney donation among African-



Americans," Baliga said. "While our findings are consistent with studies on barriers to kidney donations from cadavers, we identified barriers unique to living donors, as well. Some of these barriers, such as existing conditions, will be difficult to surmount, but much more work needs to be done to explore and overcome barriers in the African-American community."

Baliga's study is part of an NIH-funded research project addressing the sources of racial disparities in kidney transplantations and other areas of health care. Researchers are now focusing on the extent of distrust, fear and other barriers, and attempting to arrive at methods health practitioners can use to reduce those barriers. ●

Make Health a "Family Reunion" Affair

Help Your Family Make The Kidney Connection
National Kidney Disease Education Program

Many of us know family members who have diabetes or high blood pressure or both. What you may not know is that these conditions are the two leading causes of kidney failure. That's why it is important to talk with family members about what they can do to protect their kidneys. The Kidney Connection Guide, developed by the National Kidney Disease Education Program (NKDEP), will help you talk to your family about the connection between diabetes, high blood pressure, and kidney disease at your family reunion.

Diabetes and high blood pressure cause about 70 percent of kidney failure cases. About 20 million Americans have kidney disease, and nearly 20 million more are at risk. African-Americans are approximately four-times more likely than Caucasians to develop kidney failure.

You don't have to know a lot about health to share this important information with your family. The Kidney Connection Guide contains everything you need, including fact sheets about kidney disease, diabetes, and high blood pressure.

It also outlines three sample approaches for communicating the information to your family, including presenting a 15-minute Make The Kidney Connection health overview, conducting one-on-one discussions with family members at risk, and distributing kidney disease information to attendees. You can use one or more of these approaches, or create your own.

Call 1-866-4 KIDNEY or visit
www.nkdep.nih.gov/familyreunion
to get the free Kidney Connection Guide.

The National Kidney Disease Education Program is an initiative of the National Institute of Diabetes and Digestive and Kidney Diseases, one of the National Institutes of Health. ●

Are you at Risk?

By: Heather Powell, Network13 PAC Member

Kidney disease: are you at risk? Do you know the causes of kidney disease? If you were diagnosed would you know what that meant for you? Would you know your options and available treatments?

You may be thinking, "I don't have to worry about kidney disease. There is no history in my family. Why should I be interested in learning about it?" Here's why. Kidney disease is a precursor to heart disease, heart attack and stroke. It's estimated that 41 million Americans have kidney disease.

There are many causes. Heredity is just one. People with a family history are at greater risk, but so are the elderly, minorities, people who are overweight, genetic disorders, drug abuse, prostate cancer, urinary tract infections, kidney stones, the list goes on and on. Kidney disease can affect anyone at any age.

The two leading causes of kidney disease in the United States today are diabetes and high blood pressure. The scary part is these two diseases are common and on the rise (especially in children). The good news: you can treat these two causes with diet, exercise, and/or medication. My advice is to keep a check on your blood pressure and be screened for diabetes regularly. You can request your doctor do a urine test to check kidney function by screening for protein in your urine.

Your kidneys may be a small part of your body, about the size of your fist, but they do mighty work. They remove waste products, balance fluids and balance the body's chemicals in your blood. Your kidneys release three hormones: rennin, which helps control blood pressure; erythropoetin, which helps the production of red blood cells; and calcitrol, which helps maintain healthy bones. What are the warning signs you should be aware of? They include: burning or difficulty during urination, more frequent urination, passage of bloody-appearing urine, puffiness around eyes, swelling of hands and feet, pain in the small of back just below the ribs, and high blood pressure. Warning signs can be different for different people. Be aware of your body. When you don't feel well, don't ignore your body. See a doctor. Read the signs your body sends to you.

There are many obstacles to our health. Being educated about risk factors, disease, and options can make these obstacles easier to face. That is why knowledge is important...it may not prevent you from getting the disease but it will better prepare you to deal with it. ●

Helping Educate And Motivate
People Living With Chronic Kidney
Disease

Kidney Concerns Evaluation

We are interested in what you think about the Kidney Concerns. Please take a few minutes to fill out this questionnaire and send it back to the Network.

Please check just one box for each item	Disagree	Neutral	Agree	Does not apply
Kidney Concerns is easy to read				
I learn new information about my kidney disease				
I learn new information about treatment options: hemodialysis, peritoneal dialysis (PD), transplant				
The articles on diet and food helps me				
The Medicare Part D information is helpful				
I know how to contact Network 13 if I have a problem at my facility from <u>Kidney Concerns</u>				
Reminders to get my flu and pneumonia shots help me				
Links to patient educational materials and Web sites help me				
Information on Dialysis Facility Compare Web site has helped me learn how well my facility does with treatment outcomes				
Information on preparing for disasters helps me				
I share <u>Kidney Concerns</u> with others to help them learn about my kidney Disease				

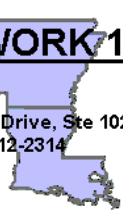
I would like Kidney Concern to have more information on: (Please Check All that Apply)

- | | | | | |
|---|---|---|---|--|
| <input type="checkbox"/> Home Hemodialysis | <input type="checkbox"/> Self Care | <input type="checkbox"/> Transplantation | <input type="checkbox"/> Exercise | <input type="checkbox"/> Work Programs |
| <input type="checkbox"/> Caring for Vascular Access | <input type="checkbox"/> Daily Dialysis Stories | <input type="checkbox"/> Patient Success | <input type="checkbox"/> Support Groups | <input type="checkbox"/> Money Issues |
| <input type="checkbox"/> Kidney Friendly Recipes | <input type="checkbox"/> Fluid Management | <input type="checkbox"/> End of Life Care | <input type="checkbox"/> Solving Problems | <input type="checkbox"/> Changes in Medicare |

Thank you for completing this Evaluation.
Your answers are important to us.

ESRD NETWORK 13

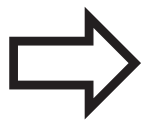
4200 Perimeter Center Drive, Ste 102
Oklahoma City, OK 73112-2314
(405) 942-6000
www.network13.org



Please Fold and Place Tape Here
(DO NOT STAPLE)



PLEASE TEAR ALONG THE LINE



Understanding Food Labels

By: Susan Knapp, MS, RD, LD,
Network 13 Medical Review Board Member

What can you learn from that fine print on the label? Since 1974 there have been regulations regarding nutrition labels. These have been updated a few times over the years. The Food and Drug Administration (FDA) regulates the labeling of the majority of foods. Meat and poultry products are under the Food Safety and Inspection Service (FSIS) of the Department of Agriculture. Most foods must have nutrition labels. However, nutrition labels are optional on some foods such as plain coffee and tea, some spices, flavorings, ready-to-eat foods prepared on site, and raw produce. Trans fats are now required on the labels, effective January 2006.

The food label includes several sections: the nutrition panel, the ingredient list, manufacturer contact information, and possibly some health claims. Following is a description of types of information that may be helpful to follow a renal diet.

The Nutrition Panel – “Nutrition Facts” and Daily Values:

Example Nutrition Panel:

Nutrition Facts		
Serving Size 1 cup (228 g)		
Servings Per Container 2		
Amount Per Serving		
Calories 250	Calories from Fat	
% Daily Value*		
Total Fat 12 g		18%
Saturated Fat 3 g		15%
Trans Fat 2 g		
Cholesterol 30 mg		10%
Sodium 470 mg		20%
Potassium 310 mg		9%
Total Carbohydrate 31 g		10%
Dietary Fiber 0 g		0%
Sugar 5 g		
Protein 5 g		
Vitamin A		4%
Vitamin C		2%
Calcium		20%
Phosphorus		20%
Iron		4%
* Percent Daily Values are based on a 2,000		
	Calories	2,000
Total Fat	Less than	65g
Sat Fat	Less than	20 g
Cholesterol	Less than	300mg
Sodium	Less than	2,400mg
Total Carbohydrate		300g
Dietary Fiber		25g

The “Nutrition Panel” part of the label has the serving size and how many servings are in that package. In this example, you can see that there are two servings of one cup each. All of the nutrition facts are given per serving. This includes calories, protein (grams), carbohydrate (grams), fat (grams), sodium (milligrams), and several other nutrients. Thus if you eat the entire package, you would be eating double the listed calories and the other nutrients. If the food is fortified or enriched with other nutrients, these must also be included on the nutrition panel. That is why you often find a more complete label on cereals because they are often fortified with vitamins and minerals. On this part of the label, nutrients may be stated as a “Percent of Daily Value” (DV). This again includes calories, protein, fat, carbohydrate and various vitamins and minerals – but as a percentage of a 2000 calorie reference diet. **Labels do not have to list phosphorus or potassium** – this is voluntary. If this information is given, it may be listed either as milligrams or percent DV. The DV for phosphorus is 1000 milligrams. The DV for potassium is 3500 milligrams. Thus – if a product has 20% DV of phosphorus and 20% DV of potassium – it has about 200 milligrams of phosphorus and 700 milligrams of potassium. Remember since phosphorus and potassium information is optional, the food can still be high in either one or both of these even though they are not listed on the nutrition panel.

Ingredient List:

Example Ingredient List:
 INGREDIENTS: SUCROSE, DEXTROSE, CITRIC ACID, SALT, SODIUM CITRATE, NATURAL LEMON AND LIME FLAVORS WITH OTHER NATURAL FLAVORS, MONOPOTASSIUM PHOSPHATE, YELLOW 5

Foods with more than one ingredient must have an ingredient list on the label. This part of the label lists ingredients by weight from the largest to the smallest. So, whatever is listed first here is mainly what this product has in it. On the other hand, if there are several ingredients and something is listed towards the end, there may not be much of it in there. Besides avoiding food ingredients that you know are high in phosphorus or potassium (such as cheese or potatoes), watch for things that have “phosphate” or “potassium” as part of the ingredients listed. Examples are phosphoric acid, sodium phosphate, monocalcium phosphate, dicalcium phosphate, monopotassium phosphate, or potassium chloride. It is best to avoid or limit foods containing these in the ingredient list, particularly if it is towards the beginning of the ingredient list. To complicate things a bit more, some ingredients that are used as preservatives or additives are better absorbed into the body than



phosphates that are normally found within food. In other words, the phosphorus from preservatives and additives more easily gets into the blood stream and raises the phosphorus level. An example of this is “phosphoric acid”, which is often found in carbonated bottled and canned beverages. Because phosphoric acid is well absorbed, if a beverage has phosphoric acid listed on the ingredient list, it is best to avoid that drink entirely – even if it isn’t listed early in the ingredient list.

Manufacturer:

The label will also provide the name and contact information for the product manufacturer. This may be a mailing address, telephone, email address and / or a website. If the nutrition facts part of the label does not have all of the information that you need, you or your dietitian can contact the manufacturer directly for this. They may have analyzed the product and be able to provide you with that information.

Nutrient Content Claims:

These are guidelines from the FDA on what terms can be used on labels. Some of the most helpful are listed below. All of these descriptions are per serving.

- ◆ “Reduced” - means 25% or less of ... (whatever they are referring to - calories or other nutrient).
- ◆ “Good Source of” – means it has 10% or more of the Daily Value of ...
- ◆ “High in” - means it has 20% or more of the Daily Value of ...
- ◆ “Low Sodium” – less than 140 milligrams of sodium per serving.

Health Claims:

There are certain claims that may be made for foods that may reduce the risk for certain diseases. This includes claims about heart disease and fat, or high blood pressure and sodium.

How does this fit into the Renal Diet?

Every patient on dialysis has individual special nutritional requirements. Other medical conditions such as diabetes also need to be considered. Your dietitian will individualize your diet according to your specific needs. When reading a food label, consider what your diet recommendations are and your intake for the rest of that day. For example, if your total allowance for sodium is 2000 milligrams per day and you eat three meals per day, your sodium intake per meal should be about a 1/3 of 2000 milligrams, or about 700 milligrams. Similarly, if your recommended potassium allowance is 3000 milligrams per day, you should aim for about 1000 milligrams per meal.

Talk to your dietitian if you need help deciphering food labels or have any questions about your diet recommendations.

References / Resources:

- <http://www.cfsan.fda.gov>
- <http://www.fda.gov/fdac>
- www.eatright.org
- <http://www.nhlbi.nih.gov/chd/Tipsheets/readthelabel.htm>

**Making Education Fun:
Word Find Challenge**

Label Reading Word Search

Find the following words:

- | | | |
|---------------------|------------|---------------|
| Nutrition, | Claims, | Carbohydrate, |
| Facts, | FDA, | Serving, |
| Label, | FSIS, | Trans, |
| Ingredients, | Nutrients, | Manufacturer, |
| Phosphoric Acid, | Fiber, | Content, |
| Potassium Chloride, | Calories, | Health, |
| Daily value, | Protein, | Phosphorus. |
| Sodium, | Fat, | |

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

See Next Page for Answers

End Stage Renal Disease Network 13
 4200 Perimeter Center Drive, Ste 102
 Oklahoma City, OK 73112-2314
<http://www.network13.org>
 Call Toll Free: 1.800.472.8664 for details.
 Local: 405.942.6000
 Fax: 405.942.6884 (main)

Dialysis Facility Compare

Where do you go when you need information on other dialysis facilities in your area? A patient asks what unit in his area offers peritoneal dialysis or home dialysis, could you tell whom to contact? You have a patient that needs evening dialysis due to his job, could you tell him what unit offers evening hours? You want to compare your facility's quality measures with the units in your area, is there a place to go to find this? Now you can. The Dialysis Facility Compare (DFC) Web site www.medicare.gov provides both demographic information and 'quality measures' data about dialysis facilities that have been approved by Medicare.

What are the three quality measures?

- ✦ The percent of patients at a facility with Urea Reduction Ratio (URR) of 65 or greater (known as 'adequacy of hemodialysis').
- ✦ The percent of patients treated with Epogen® with a Hematocrit of 33 or greater.
- ✦ Patient survival information.

The Web site also offers the dialysis facility characteristics.

- ✦ Address and telephone number of the facility
- ✦ The facility's initial date of Medicare certification
- ✦ Shifts starting at 5 PM or later (if you need your treatments in the evening)
- ✦ The number of treatment stations
- ✦ The types of dialysis offered (in-center hemodialysis, peritoneal dialysis, and home hemodialysis training)
- ✦ Facility ownership type (profit or non-profit)
- ✦ Chain name (if applicable)

Answers to puzzle on page 10:

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

What Are My Options If I Have A Grievance?

STEP 1

- Try your facility first...
- Contact your facility's social worker...
- Ask for and follow the facility's written grievance procedures...
- If not satisfied...

STEP 2

- Contact the Network...
- Ask for the Patient Grievance Policy...
- Visit our Web site for a copy of the policy...
- Speak with the person in charge of Patient Services.

What is a grievance?

A grievance is any concern about treatment in a dialysis or transplant facility. A grievance may be filed by the patient, a family member, or another person acting on the patient's behalf (per HIPAA guidelines). Grievances referred to the Network are processed according to written grievance procedures.

What is the Network?

Network 13 is under contract with the Centers for Medicare & Medicaid Services to serve the states of Arkansas, Louisiana, and Oklahoma. The Network collects patient information and works to improve patient care in dialysis and transplant facilities. Processing written grievances and trying to resolve patient concerns is an important part of the quality improvement program.

Call 1.800.472.8664 for details.
End Stage Renal Disease Network 13
4200 Perimeter Center Drive, Ste 102
Oklahoma City, OK 73112-2314

Tel: 405.942.6000
Fax: 405.942.6884 (main)
Fax: 405.942.6181 (data)
<http://www.network13.org>

ESRD NETWORK 13

4200 Perimeter Center Drive, Ste 102
Oklahoma City, OK 73112-2314
(405) 942-6000
www.network13.org

Kidney Concern July 2006

In this issue you will find:

- 1 + Lessons Learned: Even the Best Intentions
+ MedlinePlus® Adds Tutorial on Evaluating Internet Health Information
- 2 + Educate Yourself!
+ RSN's "Kidney Talk!" Hit The Airwaves in June
- 3 + 25 Years and Going Strong
+ Upcoming National and Network Patient Conferences
- 4 + Cool 'n' Crunchy Chicken Salad
+ Top Ten Fluid Tips
+ Medicare Announces Special Election Period for Low-Income Beneficiaries and Those Affected by Katrina
- 5 + Treatment Options
+ Study Identifies Barriers to Kidney Donations
- 6 + Make Health a "Family Reunion" Affair
+ Are you at Risk?
- 7 + Kidney Concern Evaluation
- 9 + Understanding Food Labels
- 10 + Making Education Fun: Word Find Challenge
- 11 + Dialysis Facility Compare
+ What Are My Options If I Have A Grievance?



KIDNEY CONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for Fall/October. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

Kidney Concerns
ESRD Network 13
4200 Perimeter Center Dr, Ste 102
Oklahoma City, OK 73112-2314
1-800-472-8664
<http://www.network13.org>