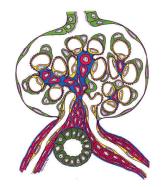
A Newsletter from the Glomerular Disease Collaborative Network

Fall 2010

Approved by the UNC-CH Institutional Review Board 9/20/2010

KIDNEY CARE



Health care professionals and patients working together to learn more about diseases that affect the filters (glomeruli) in the kidney.

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Many Thanks to our Sponsors:







PATIENT PERSPECTIVE: DÉJÀ VU AND SO MUCH MORE.

By Deidra Hall, Board Chair, Kidney Coaching Foundation

Have you ever had that all too familiar feeling that you've been there before? The situation is so familiar that you can almost say what's going to happen next. You're having a conversation with a friend and you have that puzzled look on your face like "Gosh, we JUST did this." Or you're driving and you go past that same convenience store with the big red circle on the front (ok, admittedly, I've done this before and it wasn't déjà vu, I was just plain old lost!). Either way, you know you've felt the feelings, heard the words, and had the experience once before and it may not be something you want to experience again.



Well I had my déjà vu moment just last year. See, I had just celebrated my 15 years of a healthy transplanted kidney. My mother was my donor (and yes, I do owe her at least a card every mother's day...after all she gave me life TWICE and she doesn't let me forget it!). She and I, along with our families, celebrated in Wilmington, NC with a day at the beach. Shortly after, I got a call from my doc and I heard those all too familiar words - "We got your labs back, and your creatinine is a little higher than we'd like"....here we go again.

From that point on it was a downward spiral. People, I've seen things...things I've never wanted to see again, like hospital and surgery rooms, biopsy needles, and those darn dreaded peritoneal dialysis machines (although they have gotten smaller over the years...imagine that!). I had to relearn things I learned over 15 years ago – washing your hands, keeping things sterile, what you can, can't eat...yada yada yada...déjà vu!

Continued on next page...

KEEPING YOUR JOB WHEN YOU NEED DIALYSIS

If you are working when you learn your kidneys are failing, some of your most urgent questions may be about your job. Each year, half of all people who start dialysis in the U.S. are under 65. You are not alone. It is possible to feel well enough to work on dialysis and to make your treatment schedule fit your job—IF you plan ahead. We'll tell you why—and how—to keep your job.

Fight fatigue

Do you feel too tired to work? Failing kidneys make less of a key hormone (*erythropoietin*, or EPO). EPO tells your bone marrow to make red blood cells, which bring oxygen to your cells. When you don't have enough red blood cells, you have *anemia*. Most people with stage 4 or 5 chronic kidney disease (CKD) have anemia, which can make you feel:

- Tired
- Mentally Fuzzy
- Weak
- Cold all the time
- Short of breath

Anemia can also cause pale lips, gums, and nail beds. In men, it can cause erectile problems. And, some people crave ice, clay, laundry starch, or dirt when they have anemia.

Continued on next page...

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Patient perspective continued..

But during this whole ordeal, there was one thing that was new to me. Now, I make no apologies, I'm a Christ-follower. And having the knowledge and faith that I have now was something I didn't have as a kid. Somehow as a kid, I just knew things would be ok. But now I knew that I knew that things would be fine. I dug deep and read my bible. There were three verses that I repeated, prayed and clung to dearly (I do believe in speaking things into your life).

"But I will restore you to health and heal your wounds,' declares the Lord". - Jer. 30:17

"Because he loves me," says the Lord, "I will rescue him; I will protect him, for he acknowledges my name. He will call upon me, and I will answer him; I will be with him in trouble, I will deliver him and honor him. With long life will I satisfy him and show him my salvation." - Psalm 91:14-16

"When Jesus heard that, he said, This sickness is not unto death, but for the glory of God, that the Son of God might be glorified thereby."- John 11:4

Those verses taught me something. I didn't (and don't) have to worry about the end of this journey. There's evidence in what I'm reading that I will be ok.

Now why am I sharing this with a mass audience? I am almost sure, there are some reading this that don't have the same belief that I have and then again, there are some that do. Either way, there are some, that just need to hear, see or read something, a comforting word that this kidney journey they are on can and will be alright. I found strength in those verses. I found courage in those verses. In a swirl of what seemed to be never ending ups and downs, I found my mojo in those verses! Although this was a déjà vu moment, and I knew how the story went, I still needed to know that THIS ending would be just like the last – I would live, I would be ok. And you know what? I am! Since March of this year I got my second kidney from my sister, and I'm living life on full speed.

Kidney disease can seem never ending. It can even be down right annoying, especially if it's been more than once that you've been through it. But just like with déjà vu, we give it a puzzled look, shake our head, take a deep breath and move through it until wewait, didn't we have this conversation once before? Hmm, weird....

Keeping your job continued from page 1...

Anemia can be treated, and you can have more energy. But many people don't get treatment. Sadly, some even quit their jobs, thinking they'll never feel well enough to work. By the time they start dialysis and get their anemia treated, it's often too late to go back.

Don't let this happen to you! Anemia can come on slowly. You may not notice it at first. Ask for a blood test to be sure. If your red blood cell level is low, talk with your doctor. Iron pills and a form of EPO called Aranesp® or Procrit® are used to treat anemia. **NOTE:** The FDA has put a "Black Box" warning on EPO drugs, which have caused harm in some people with cancer or heart problems. Talk with your doctor about the risks and benefits for YOU—and keeping your job.

Earn more than disability pays

Permanent vacation...no deadlines, no more boss. Sound good? What most people don't know is that Social Security Disability Insurance (SSDI) may only pay about 35% of what you earn at work. To prevent fraud, even a private disability plan will replace just 60% of work income (minus SSDI payments).¹ This means most people can earn much more money from work than they would get from disability.

Think about it: what would *you* have to do without if you had just 1/3 or even 2/3 of your current income? Could you keep your home? Your car? Could you eat a meal out or take a trip? Could you help send your kids to college? Think long and hard before you decide to take disability. Once you do, it can be very hard to go back to work in the future.

Continued next page,

"There are some that just need to hear, see or read something, a comforting word that this kidney journey they are on can and will be alright."

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Keeping your job, continued from page 2

Stay healthier and feel better

Research shows that people on dialysis who keep their jobs *feel better*. They are more physically able, with less pain. They have better general health and energy.² And better physical function means they may have fewer and shorter hospital stays—and live longer.³ Of course, people who feel better in the first place are more likely to work. But a job can also give you a sense of *purpose*, a place to be, an identity, and income. Those things can help you feel good about yourself and your life.

People with CKD who work are also far more likely to have a health plan through work.⁴ An employer group health plan (EGHP) can help pay for treatment and drugs Medicare does not cover. You may be better able to afford to follow your care plan if you keep your job.

Choose a work-friendly option

Plan ahead if you can. You know your work schedule and whether your job includes travel. If you have a living donor, you may be able to plan to get a kidney transplant before you need dialysis. This is *preemptive transplant*. If not, choose a form of dialysis that will be "work-friendly" so you can:

- Work during normal work hours
- Feel your best between treatments
- Travel for work if you need
- Have a normal or near-normal diet

Standard in-center hemodialysis

Dialysis clinics offer hemodialysis (HD) three times a week (MWF or TThS). A plastic filter called a dialyzer cleans the blood. Blood goes to the *dialyzer* through tubing that connects to two needles in your arm. Treatments last 3–4 hours (just 9–12 hours out of 168 in a week), so they require strict diet and fluid limits, and you need to take (and pay for) many meds.

You may be able to get a shift early in the morning or in the evening after work. For some, this is work-friendly. They bring a laptop and/or cell phone (if the clinic allows it) and do work. For others, the "dialysis hangover" of taking off extra fluid just three times a week leaves them washed out, with flu-like symptoms after treatments, and fuzzy thinking all the time.

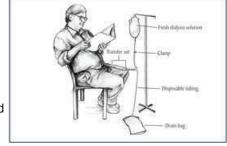
In-center nocturnal HD

What if you could get treatments at night, while you sleep—in the clinic? This is *in-center nocturnal HD*, and more clinics are starting to offer it. These treatments don't take time out of your work day. With more than twice as much treatment, people feel better, stay out of the hospital more—and live longer.⁵ Plus, there are fewer meds to take and fewer fluid limits. Treatments tend to start at 8 or 9 pm and end at 4 or 5 am.

Peritoneal dialysis (PD)

PD uses the inner lining of the belly (the *peritoneum*) as a sac to hold sterile fluid. Fluid goes in through a plastic tube (*catheter*) placed by a surgeon. Wastes and excess water flow into the fluid. Used fluid is drained out and fresh is put in, in a process called an *exchange*. No needles are used for PD, and your blood stays in your body. Since your blood is cleaned most or all of the time with PD, there is no "dialysis hangover" and your meal plan will be more normal. You can do:

- Continuous ambulatory PD (CAPD): Do exchanges by hand at breakfast, lunch, dinner, and bedtime. Bring a bag to work to do a lunchtime exchange (you'll need a clean room to avoid infection).
- Continuous cycling PD (CCPD): Use a cycler machine to do exchanges at night while you sleep. You may also need to do one daytime exchange by hand.



Home HD

If you choose home HD, you can do your treatments on your *own* time—like morning one day and evening the next. Your clinic will provide a machine, supplies, and training. (You don't have to buy a machine). Most programs will want you to have a partner to train with you and be there in case you need a hand. Home HD is very work friendly:

- **Nocturnal home HD (NHHD)**: Do treatments at night while you sleep, 3–6 nights per week. NHHD leaves your days free for work, and offers a normal or near-normal diet and fluids, with fewer drugs and no "dialysis hangover."
- Daily home HD (DHHD): Do short (2–3 hour) treatments 5–6 days a week in the early morning or after dinner while you watch TV. The frequent treatments prevent "dialysis hangover," and the diet is more normal than in-center HD.
- **Conventional home HD**: Do treatments three times a week (or every other day) on your own schedule at home. Dialyze longer if you need to remove more fluid and wastes. *Continued next page...*

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Keeping your job, continued from page 3

Find a center that offers your choice

Many of the 5,200 or so dialysis centers in the U.S. offer in-center HD only. You may have to do some homework to find a center that offers a more work-friendly option. About 40% of U.S. centers have PD, and about one in ten has home HD. You may also need to change doctors if your doctor does not support your choice. Research shows that people who choose their dialysis option *themselves* live longer. *And*, they are more likely to get a transplant than those whose doctor chooses for them— or even those who work with their care teams to make a choice.⁶ This makes sense, since *you're* the one who must live with your choice each day.

On the Home Dialysis Central website (http://www.homedialysis.org/locate) there is a database of U.S. clinics that do home or in-center nocturnal treatments. You can look up clinics by state, or even by your town. If you live near a state border, the nearest center may be in the next state. Once you find a center, you will see contact information, which treatments it offers, and a map to help you find it.

Plan for your training and set-up needs

It takes a week or two to train for PD. Most programs will do a home visit to help you choose a room for PD exchanges and figure out where you will store your supplies. You may be able to use vacation or sick days to have your PD catheter placed and train for PD. If you know this is coming, you can plan to save up your vacation or sick days. Or, if your company is large enough (50 or more employees), you may be able to use the Family and Medical Leave Act (FMLA) to ask for unpaid time off. Plan on one clinic visit per month to check your blood pressure, do blood tests, review your treatment logs, and see if you need any changes to your treatments. If you get an infection, you may miss some work time.

Training for home HD takes longer—usually 3–6 weeks. Many programs require a home visit. For some older types of machines, plumbing and wiring changes are needed to your home. Some centers will pay for this. Others will pass these costs on to you. You may need to take a temporary leave of absence from work for your access surgery and home HD training, unless you have enough vacation or sick time. Your home HD partner will also need to take some time off work, since training is mostly done during work hours. Talk with the home training nurse if this is a problem. You may be able to arrange a training schedule that will minimize time lost from work.

Conclusion

Kidney failure *will* change your life—but how much and in what ways is largely up to you. Plan ahead and choose a work-friendly treatment to feel your best and reduce the impact of CKD on your lifestyle and income.

To learn more, download and read A Kidney Patient's Guide to Working and Paying for Treatment. (http://www.lifeoptions.org/catalog/pdfs/booklets/employment.pdf)

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HEALTH REFORM—WHAT CAN YOU EXPECT?

By Caroline Jennette, MSW, Social Research Specialist, UNC Kidney Center

In March of this year, historic legislation was passed to reform the American health care system as we know it. For better or for worse (depending on how you feel about health care) major changes are happening that effect all health care consumers.

Closing the Medicare Part D "Donut Hole"

After June 10 and through the rest of 2010, if you reach the Medicare Part D "donut hole" and are NOT enrolled in or eligible for the Medicare Extra Help Program you will be mailed a one-time, tax free check for \$250. If you reach the donut hole next year (2011), you will get a 50% discount on brand name prescription drugs.



Coverage for Consumers with Pre-Existing Conditions

The new, federally funded Pre-Existing Condition Insurance Plan (PCIP) is now open for enrollment in most states. The PCIP was created to be a bridge until 2014, when pre-existing conditions will not be allowed to be an exclusion criteria for any health insurance plan.

The advantage of the federal plan that may be especially helpful to kidney/chronic disease patients is that there is no waiting period for pre-existing conditions. Transplant recipients who are expected to lose Medicare coverage after 36 months may benefit as they cannot be turned away due to their pre-existing condition. Unfortunately, premiums will still be somewhat high, but can only be 100% of the standard risk rate (the average premium of the top insurance companies). To be eligible for PCIPs, you need one letter from an insurance company denying you medical coverage, and you must have been uninsured for the previous 6 months.

Coverage for Young Adults

Starting September of this year, all health plans that provide dependent coverage for children will be mandated to extend benefits to these dependents through age 26, even if the dependent is not in college (typically plans may cover young adults in their twenties but only if they are enrolled in college). This will be especially helpful for young adults with kidney disease who cannot afford an individual health plan. Many private plans started enrolling these young adults earlier in the year, so check with your own insurance plan about coverage options.

Preventive Care

New health plans that began coverage after September 23, 2010 and existing health plans that make "significant changes" after that date will be required to offer multiple preventive care services with no deductible, co-pay, or co-insurance required, but insurers will typically be allowed to charge for goods and services needed to treat a condition detected in a screening.

Preventive services with a recommendation of "A" or "B" from the US Preventive Services Task Force (USPTF) must be covered. You can see a list of those services here: http://www.ahrq.gov/clinic/uspstf/uspsabrecs.htm. Immunizations for children and adults and well-baby visits will also be covered.

Also, starting in January 2011, Medicare patients will be able to receive annual, full physicals (currently, they get one "Welcome to Medicare" physical during the first 6 months of enrollment. Preventive services will also be covered with no out-of -pocket costs (a full list of these services is still in development but will most likely mirror USPTF recommendations). It is hoped that an annual physical and greater coverage for preventive care will help diagnose health conditions earlier to better manage and slow the progression of chronic diseases.

Individual and Employer Mandates

Starting in 2014, individuals will be required to have health insurance, and employers with 50 or more employees will also be required to cover their workers. Private insurance companies will advertise their plan benefits through a health care exchange, where consumers and small businesses will be able to pick and choose form a "menu" of plans. The details of the mandate are still being worked out.

For more information on what health reform means for you, please check out www.healthcare.gov

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PHYSICAL ACTIVITY, EXERCISE, AND CHRONIC KIDNEY DISEASE

By Connie Gilet, MSN, Adult Nurse Practitioner, UNC Kidney Center

In the general population, the benefits of physical activity and exercise are well known. There is documented evidence to support the statements that physical activity and exercise can:

- Help people control or lose weight if combined with a healthy diet;
- Decrease the risk of heart attack or stroke;
- Lower the risk of developing diabetes or help to control blood sugars in people who have diabetes:
- Lower the risk of some cancers (for example, colon cancer and breast cancer);
- Strengthen muscles and bones;
- Help with balance and walking to prevent falling in the elderly;
- Improve overall mental health and feelings of well being.



It is not yet known if all the above benefits of physical activity and exercise for the general population apply to those with chronic kidney disease (CKD). Current research does suggest, however, that physical activity and exercise in those with CKD may:

- Help control cholesterol levels;
- Improve muscle mass, which can help physical performance;
- Help with controlling or losing weight;
- Help with blood pressure control;
- Improve a person's sense of well being. This includes helping combat depression, anxiety and stress;
- Help with controlling blood sugars in those who have diabetes.

While more safety guidelines and detailed exercise guidelines need to be developed for those with CKD, here are some general guidelines.

- Exercise should be appropriate for an individual's level of fitness and safe for his/her clinical condition.
- In general, exercise is not recommended if:
 - o Your blood pressure is greater than 200/100;
 - O You have had a recent heart attack or at risk for a heart attack;
 - O Your blood sugars are too high or too low;
 - You have electrolyte abnormalities, for example, potassium or calcium imbalances;
- Consult with a physician or health care provider for guidance or recommendations specific to your situation and before starting an exercise program.

There are three types of exercise: 1) aerobic, 2) resistance training and 3) flexibility and stretching. Aerobic exercise includes activities such as walking, running and swimming. Resistance training includes working with weights while flexibility and stretching exercises work to maintain range of motion and improve gait (how you walk), balance and coordination. Ideally you should be involved in all three types of exercise on a regular basis. You should be able to breathe and talk comfortably while you exercise. If you are winded or unable to talk, slow down.

It is not necessary to join a gym to engage in regular exercise. For example, you can walk around the block near your house or around the indoor mall when it's raining for aerobic exercise. For resistance training, you can sit in a chair raising your foot off the floor to exercise your leg muscles. Flexibility can be improved by balancing yourself while standing on one foot. Start slowly with small amounts of exercise and gradually increase your activity level. It may take weeks to months to see any results from your efforts. So be patient, regular exercise will help you feel better.

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IMMUNOSUPPRESSIVE MEDICINE FOR TRANSPLANT: MEDICATION MATTERS

By Lara Tushla, LCSW, NSW-C, Transplant Social Worker, Rush University Medical Center

Health care is always changing and transplant is no different. One change that has been effecting transplant patients is the availability of generic version of two anti-rejection medications - CellCept® and Prograf®.

The question about whether generic medications are an option for you... is a conversation you need to have with your Transplant Team.



We have been hearing some things from our patients:

- 1. They don't make the brand name medicine anymore.
- 2. Medicare won't cover the brand name version.
- 3. Your copay for the brand name medicine is now several hundred dollars per month.
- 1. CellCept and Prograf are still being made. As I understand it, it is often a reimbursement issue for the pharmacy which makes it financially difficult for pharmacies to dispense the brand name version.
- 2. The Medicare question is one of billing rates. Medicare has one code whether you take brand CellCept or generic mycophenolate mofetil. The same goes with Prograf. Medicare reimburses the pharmacy the same amount whether you get the brand or generic version of these medicines. Where the challenge is for the pharmacies, is that the reimbursement rate works the same way. So the reimbursement for the brand name medicines is not very good for the pharmacies. They may be losing money if they give you the brand name drug.
- 3. One of the hardest parts of all of this is the financial impact and stress it can have on transplant recipients. When you hear that there are big copays, you have a few options. The first step is to double check your prescription coverage. You can call your insurance company to check the copays for both the brand and generic versions of the medicine ask for both 30 and 90 day supplies. We have been finding that some insurance companies are not only changing the brand level copay, but also difference between the cost of the brand and generic, apparently known as an "ancillary fee" or "penalty fee." This can come to several hundred dollars for a monthly copay.

Another option is to contact the assistance programs for these medicines. They can help investigate your copays and identify options, including some of the resources below:

- 1. Copay assistance cards: The makers of CellCept, Prograf, Myfortic, and Neoral have cards that can discount your copays. (NOTE: Myfortic is <u>not</u> available in a generic version).
 - a. However, these cards cannot be used for Medicare (Part B or D), Medicaid, or TriCare copays.
 - b. Your transplant team has access to these cards and can provide them to you.
- **2. Foundation:** The Healthwell Foundation can sometimes help with copays on anti-rejection medicines: 800-675-8416 or www.healthwellfoundation.org
 - a. Approval is based on household income and availability of funds.
- **3. Patient Assistance Programs:** The companies that make the anti-rejection medicines have programs that offer free medicine depending on your income and insurance situation. Here are a couple of good websites that provide information about most patient assistance programs in addition to contact numbers: www.rxassist.org and www.needymeds.com
 - a. Astellas (Prograf): 800-477-6472
 - b. Novartis (Myfortic and Neoral): 800-277-2254
 - C. Roche (CellCept): 866-247-5084 (There is also assistance with Valcyte through this program)
 - d. Pfizer (Rapamune): 888-327-7787

NOW ENROLLING: LOWERING SALT INTAKE IN CHRONIC KIDNEY DISEASE

Salt restriction remains an underexplored and underused treatment in patients with mild to moderate chronic kidney disease (CKD). Nephrologists, Dr. Philip Klemmer and Dr. Vimal Derebail, are conducting this research study.

Research study visits will occur in the UNC Clinical and Translational Research Center (CTRC). Subjects, in random order, will be given 4 weeks of intensive dietary counseling to achieve a very low-salt diet (2 grams/day sodium) and then compared with 4 weeks of regular salt intake diet. This research study consists of 7 CTRC visits spaced over 13 weeks (each lasting about 1 to 2 1/2 hours) along with 6 alternate week phone calls for follow-up and dietary counseling (each lasting about 10-15 minutes). In addition to monitoring blood pressure, kidney function, blood and urine tests during the different salt-diets, we will also use a test called a bioimpedance analysis (BIA) to evaluate changes in body fluid volume.

You must:

- Be between 18-85 years
- Have Chronic Kidney Disease stages 3-4 (eGFR 20-60ml/min/1.73 m²)

You must not have:

- Sitting systolic BP <100mm Hg
- Recent illness or hospitalization
- Active psychological condition
- Amputation of a limb
- Pacemaker/defibrillator, coronary stents, or metal suture material in the heart or atrial fibrillation.
- Weight over 300 lbs

Participant requirements:

- 7 visits over a 13 week period
- 7 dietary consultations with alternate weekly phone consultations
- Four 24 hour home BP monitoring
- Blood sampling every visit
- Four BIA measurements
- Six 24 hour urine collections
- Participant reimbursement: \$25 per visit \$175 if all 7 visits completed and parking vouchers.

If you are interested in being part of this research study or know someone who might be, please contact one of our Study Coordinators, Ursula Goetz or Sarah Cheema, at 919-966-2561 ext 242 or 284, or by email at ugoetz@med.unc.edu or scheema@email.unc.edu.

Medication Matters (cont. from page 7)

When you pick up your medicines, check to make sure your medicines are right. If you don't recognize something, ask the pharmacist. The generic pills will look different, but some are similar. If you switch to a generic version of these medicines (mycophenolate mofetil or tacrolimus), talk to your Transplant Team. They will probably have you do more frequent blood tests to make sure that your levels of the medicines are stable. Also, there are a few different generic versions of each of these medicines, talk to the pharmacy to make sure that they will give you the same version of the medicine every month.

Switching to generic medicines has been done safely with transplant patients, if the Team is aware of the change and the drug levels stay stable.

Above all, when you have questions about your anti-rejection medicines, coverage, help with copays, and brand-vs-generic options... contact your Transplant Team and work with them to preserve your health and your transplanted organ.

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NOW ENROLLING: CYCLOPHOSPHAMIDE-RELATED BLADDER CANCER EVALUATION STUDY

Have you ever been treated with cyclophosphamide or chlorambucil? If the answer is "Yes," you might want to participate in our Cyclophosphamide-Related Bladder Cancer Evaluation Study.

What is this study about?

The purpose of this research study is to create a registry of patients who have received treatment for vasculitis or glomeru-lonephritis with the chemotherapy drugs cyclophosphamide or chlorambucil. These drugs are known to increase the risk of bladder cancer. For this reason, screening for bladder cancer is recommended although specific guidelines as to the frequency of such screening are not well established. Although screening for bladder cancer is offered to patients previously treated with cyclophosphamide or chlorambucil, we currently do not have a process in place to assure that all patients at risk undergo regular screenings.

The specific aims of the registry are to:

- 1. Identify patients who have been treated with cyclophosphamide or chlorambucil and are at increased risk for bladder cancer:
- 2. Offer these patients a systematic screening regimen with scheduled cystoscopies. (However, since routine screening for bladder cancer is recommended to any patient who has received cyclophosphamide or chlorambucil, the costs of the screening tests and cystoscopy will be billed to the patient and/or the patient's insurance);
- 3. Collect demographic, clinical, and epidemiologic data on factors that may influence a patient's risk for bladder cancer:
- 4. Assess whether a test done on urine samples is effective in detecting bladder cancer.

Frequently Asked Questions:

What is a cystoscopy? A cystoscopy is a procedure to examine the bladder from the inside. It is performed under local anesthesia by inserting a flexible scope (tube) in the urethra.

Do I have to do the tests at UNC? No, you can do the cystoscopy and the urine tests at another facility and ask your local physician to fax or mail us the results.

I have signed the consent form for the study, and I want to do the tests at UNC, but I have not been contacted to schedule a cystoscopy yet. Why not? In general, cystoscopies are scheduled at month 30 and 60 (2 and a half and 5 years) after the beginning of your cyclophosphamide/ chlorambucil treatment and every year after that. If you have not been contacted, it might be that you have not reached the 30 month mark yet. If you still think it's time for you to come in please call and check with Anne Froment (919) 923-1382.

How do I join the study?

If you are interested, please contact Anne Froment at (919)923-1382, <u>anne_froment@med.unc.edu</u> or, if you are a patient seen at the UNC Nephrology clinic, ask your doctor about the "cystoscopy study" next time you come in for an appointment.



Don't forget to check out our glomerular disease patient education podcasts at:

http://www.unckidneycenter.org/podcast.html

We now have podcasts for ANCA, FSGS, Fibrillary GN, IgA Nephropathy, Minimal Change Disease, and Membranous Nephropathy!

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RECIPE BOX: CHICKEN CHILL

Diet type: CKD non-dialysis

Dialysis

Diabetes



Serving size: 1 Cup Chili + 1 Cup Rice

Ingredients

- 1 tablespoon canola oil
- 4 cloves garlic, or 2 teaspoons chopped garlic in oil (jar)
- 1 cup onion, chopped
- 1 cup celery, chopped
- 1 cup carrots, chopped
- 1 cup green pepper, chopped
- 14-ounce can chicken broth, low sodium (140 mg or less per cup)
- 1-1/2 pounds (3 cups) cooked, chopped chicken
- 1 cup dark red kidney beans, canned, drained and rinsed
- 1 cup diced tomatoes, no salt added. drained
- 3/4 cup salsa, low sodium
- 3 tablespoons chili powder
- 1 teaspoon ground Mexican oregano
- 1/2 cup grated cheddar cheese
- 1/2 cup sour cream
- 4 cups white rice, cooked

Preparation

- 1. Pour oil in a large stock pot.
- 2. Sauté garlic, onion, celery, carrot and green pepper until soft.
- 3. Add low-sodium broth and bring to a boil.
- 4. Add chicken, beans, tomatoes, salsa, chili powder and oregano. Simmer for 1 hour.
- Serve 1-cup chili over 1/2-cup white rice. Top each serving with 1 tablespoon grated sharp cheddar cheese and 1 tablespoon sour cream.

Renal & Renal Diabetic Food Choices

- 3 Meat
- 1-1/2 Vegetable, medium & high potassium
- 2 Starch

Carbohydrate Choces

2-1/2

Helpful Hints

If you wish, use a stewing chicken or a pre-cooked rotisserie chicken. Pull meat from bones and chop. Boneless chicken breast, lean ground turkey or chicken are also acceptable.

Suggested low-sodium brands for this recipe include: Green Giant® red kidney beans, Nature's Promise® or Newman's Own salsa, Health Valley® canned, low-sodium chicken broth, Del Monte® canned, diced, no-salt-added tomatoes

Nutrients per serving

Calories: 355

Protein: 24 g

Carbohydrate: 38 g

Fat: 12 g

Cholesterol: 59 mg

Sodium: 348 mg

Potassium: 653 mg

Phosphorus: 270 mg

Calcium: 133 mg

Fiber: 4.7 g

Always consult with your physician, dietitian and other members of your dialysis team before partaking in any activity or trying any recipe. Find more recipes at: www.davita.com/recipes

disease been FUN? Never? Then listen to KidneyTalk—the online radio talk show that will have you laughing as you learn! With your hosts Lori Hartwell (founder and executive director of RSN) and Stephen

Furst (actor and transplant recipient).

When has learning about kidney





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FLU SEASON IS COMING: ARE YOU READY?

The Centers for Disease Control lists patients with kidney disease as a high-risk group that may face special medical challenges during flu season, and suggest that all individuals be vaccinated against the flu. The 2010-2011 flu vaccine will protect against an influenza A H3N2 virus, an influenza B virus and the 2009 H1N1 virus that caused so much illness last season.

Why get vaccinated?

Influenza ("flu") is a contagious disease. It is caused by the influenza virus, which can be spread by coughing, sneezing, or nasal secretions. Anyone can get influenza, but rates of infection are highest among children. For most people, symptoms last only a few days.

Symptoms include:

- fever
- cough
- sore throat
- headache
- chills
- · muscle aches
- fatigue



Other illnesses can have the same symptoms and are often mistaken for influenza.

Infants, the elderly, pregnant women, and people with certain health conditions – such as heart, lung or kidney disease or a weakened immune system – can get much sicker. Flu can cause high fever and pneumonia, and make existing medical conditions worse. It can cause diarrhea and seizures in children. Each year thousands of people die from seasonal influenza and even more require hospitalization. By getting vaccinated you can protect yourself from influenza and may also avoid spreading influenza to others.

Types of influenza vaccine

- 1. Inactivated (killed) vaccine, or the "flu shot" is given by injection into the muscle. ("flu shot")
- 2. Live, attenuated (weakened) influenza vaccine is sprayed into the nostrils. ("nasal spray")

Persons with kidney disease and those who are in close contact with persons who have kidney disease should NOT get the nasal spray because it is a live virus and can be damaging to already compromised immune systems.

When should I get Vaccinated?

Getting the vaccine as soon as it is available will provide protection if the flu season comes early. You can get the vaccine as long as illness is occurring in your community.

Influenza can occur at any time, but most influenza occurs from November through May. In recent seasons, most infections have occurred in January and February. Getting vaccinated in December, or even later, will still be beneficial in most years. Adults and older children need one dose of influenza vaccine each year. But some children younger than 9 years of age need two doses to be protected. Ask your healthcare provider. Influenza vaccine may be given at the same time as other vaccines, including pneumococcal vaccine.

What if I or one of my family members does not want to get vaccinated?

It is recommended that everyone receive flu vaccinations, especially those who have or are around people with chronic diseases. If you or another family member refuses to get a flu shot, here are some steps to take to avoid getting the flu.

- Wash your hands often with soap and water for 15-20 seconds (sing the "Happy Birthday song" twice). If soap and water are not available, use an alcohol-based hand rub.
- Avoid touching your eves. nose or mouth since germs spread this way.
- Avoid close contact with sick people.

For more information, check out www.flu.gov

A Newsletter from the Glomerular Disease Collaborative Network

Burnett Womack, CB#7155 Chapel Hill, NC 27599-7155

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Health care professionals and patients working together to learn more about diseases that affect the filters (glomeruli) in the kidney.



www.unckidneycenter.org

Remember to T.E.S.T Your Family Members



- T Teach them that kidney disease runs in families.
- **E** Encourage them to get tested for kidney disease.
- S Support their efforts to control their diabetes and high blood pressure.
- T Tell them where they can find more information: www.unckidneycenter.org (1-866-256-2930) or www.nkdep.nih.gov (1-866-454-3639)