

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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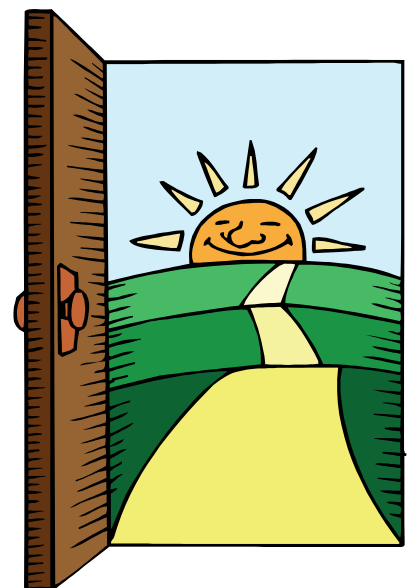
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FOLLOW THE YELLOW BRICK ROAD: A PATIENT'S GUIDE TO LIVING WITH CHRONIC DISEASE

Imagine this... you've just been diagnosed with a chronic disease and you feel like you are about to embark on a strange new journey. You don't know much about where you are, and you don't know where you're going. This scenario sounds a little like Dorothy, from the Wizard of Oz, doesn't it? Well, I'm here to tell you from experience that living with a chronic disease, in my case end stage renal disease, is a little like being in Oz. You are in unfamiliar territory, and you are going to have to make decisions that will require a brain, a heart, and a whole lot of courage. However, along the way you will encounter many people who will help you learn to live in this new world, you will make new friends and discover the amazing support network you have available to you, and, eventually, you will get your life to a place that is the "new normal" for you. Please join me as I take you down the yellow brick road to health and happiness.

First of all, you will need a lot of courage, like the cowardly lion. Courage is defined by Webster's dictionary as "the state or quality of mind or spirit that enables one to face danger with self determination, confidence, and resolution; bravery." This is perhaps the one thing that helped me most during my recent dialysis and transplant experiences. I have lived my life using the prayer of serenity as a guide. You probably remember this prayer or something like it... "God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference." The things that I decided that I could control in my life were: my positive attitude, my diet and exercise routines, and following the doctor's instructions for taking my medications and monitoring my vital signs. I could not control the rest of the things that were happening to my body, so I decided to simply accept those things, and let the medical professionals and God worry about those. That decision transformed the way I was able to react to my disease.

Next, just like Dorothy had to learn to trust the munchkins and others in Oz as they tried to help Dorothy find her way home, you will also need to build a relationship and build trust with your health care team. I call it a team, because it is a group of people all working towards a similar goal, getting you as healthy as possible so you can get back to living your "new normal" life. Along your journey there will be many people sharing their expertise with you, and telling you what they think you should be doing. You are the coach of this team, and just like a sports team coach, you need to be knowledgeable enough to be able to understand what they are telling you, and make the decisions that will serve you best. Which leads us on down the road to....



Continued next page →

“Follow the yellow brick road...have courage, knowledge, and have a heart as you travel your new life path.”

(cover story cont.)

A brain. As did the scarecrow, you already have the ability within yourself to learn and understand what you need to know to live the healthiest life possible for you. It is very important that you, your family and your friends study and understand your disease, so that you may ask questions to make sure that the treatment you receive is what is best for you. You will have to become an expert on your disease. Talk to others living with the disease, go to support groups, ask your health team for information, use the resources available whether it is the Internet or your local library to learn as much as possible about your disease so that you are a vital, active, part of your healthcare team. Understanding your disease and the effect it has on your body allows you to provide invaluable information to the members of your healthcare team and allows you to participate in your own treatment. Participating in your own treatment will empower you and provide you with the assurance that you are doing all you can do to promote wellness. Because, in the end, you are the great and powerful Oz. You have the ability within yourself to conquer this disease. You just have to tap into those abilities.

Finally, you are the heart of your healthcare team. Like the tin man, you need a heart to keep this physical body working. The heart is “the vital center of one’s being, emotions, and sensibilities”, according to Webster. While the doctors look at you as a unique and challenging case, you are a human being with a heart and soul. **You** are the center of the health care team. Without you, there is no team. You make the disease human and unique to you. Each person will react and experience the disease in a different way. You have the disease; the disease does not have you. You have within you the power to control how you react to what is happening to you. React positively, and you will find that you have a much more positive experience than those that have a gloom and doom attitude. Be kind and loving to the healthcare providers and the support team you have in your personal life. Love and appreciate these people, and tell them how important they are to you all along the way. Have a heart.

In conclusion, follow the yellow brick road...have courage, knowledge, and have a heart as you travel your new life path. Listen to those along the way as they guide you, but always make decisions based on what is best for you in your individual case. Like Dorothy, you will find your path back home, to your “new normal”. You have within you everything you need to live a happy, healthy life. If my experiences are any indication, your “new normal” will be a much more wonderful life than you ever imagined. You will have made all of these wonderful friends along the way, you will have faced and conquered life’s challenges, and you will have a new appreciation for your own abilities and strengths, and a special new appreciation for that place you call home. You are the great and powerful Oz in your life. I hope your journey down the yellow brick road is a happy and healthy journey. Somewhere over the rainbow is where you’ll find me. I hope to see you there!

Beth Holloman

Beth was first diagnosed with chronic renal failure (CRF) at age 26. She was followed by a nephrologist and was able to maintain her kidney function for 14 years through diet, exercise and meds prior to beginning dialysis. She received a kidney transplant in October 2004 from a non-related donor, a friend who was a perfect match, and has had no problems or episodes since then. She has returned to her job as a teacher and enjoys sharing her amazing success story with others.



For more kidney disease info, internet links,
and printable copies of
this newsletter, check out
our new website:

www.unckidneycenter.org

DIETARY GUIDELINES FOR DIALYSIS PATIENTS



One of the main jobs of a healthy kidney is to process the fluids and minerals from food that your body does not use for other purposes. When you lose function in your kidneys, its harder for your body to break these minerals down.

Protein: People on dialysis need to eat protein every day. Protein is needed to maintain healthy body tissues and replace cells that are normally lost each day. The type of protein you eat is very important. Most of the protein that you eat should come from **high-quality protein**. High quality protein comes from animal products such as fresh beef, pork, chicken, turkey, fish, eggs, lamb and dairy products.

Potassium: Potassium is a mineral found in foods, especially fruits and vegetables. You need potassium to regulate your heart rhythms. Dialysis patients have trouble keeping their potassium levels low. If potassium levels get too high, your heart beat could be come irregular and could even stop. Ask your dietician how much potassium you can have.

Potassium Levels in common foods (serving size = 1/2 cup):

Low Potassium (less than 150mg)	Medium Potassium (150-250mg)	High Potassium (>250mg)
Green beans, canned	Green beans, fresh	Fresh okra
Cooked carrots	Collards	Tomato sauce
Mustard Greens	Corn	Potatoes
Broccoli, raw	Fresh tomato	Parsnips
Apples	Summer squash	Winter squash
Blueberries	Watermelon	Banana
Peaches, canned	Apricots, fresh	Orange
Pears, canned	Peaches and pears, fresh	Cantaloupe

Phosphorus: Healthy kidneys remove excess phosphorus from your body. A high phosphorus level in your blood can cause itching, bone pain, brittle bones, muscle aches, and heart damage. Limiting high phosphorus foods in your diet is the first step towards maintaining a healthy phosphorus limit in your blood. Your doctor may also prescribe a “phosphate binder” that you take with food.

Sodium: Sodium is found naturally in most foods, and the main source of sodium in the diet comes from salt. One teaspoon of salt equals 2300mg of sodium. Canned foods and processed foods contain a lot of sodium. Foods that are high in sodium make you thirsty and cause your body to hold onto fluid. This can cause high blood pressure and body fluid overload, so it is best to avoid salt and foods high in sodium. **Important:** Many salt substitutes contain potassium, and should also be avoided. Try using vinegar, lemon juice, onion powder, or garlic powder (not garlic salt) instead.

Fluids: Healthy kidneys get rid of extra fluid in your body. Since your kidneys are making less urine, or no urine at all, you need to limit the amount of fluid that you drink. To much fluid will lead to high blood pressure and fluid overload, which can cause swelling, shortness of breath, and heart problems. Most people on dialysis should limit fluids to 4 cups or 32 ounces a day. Any food that is liquid at room temperature counts as fluid—ice, ice cream, popsicles, jell-o—as well as the usual things that you drink.

What if I’m a Vegetarian? Most vegetable sources of protein, like beans, soy, and grains, also have very high levels of potassium and/or phosphorus. The biggest challenge of being a vegetarian on HD is getting enough high quality protein to avoid malnutrition and muscle wasting—without getting dangerous levels of potassium and phosphorus. It can be done, though you’ll need to work closely with your dietitian.

For more information, talk to the dietitian at your dialysis clinic, or logon to www.kidneyschool.com, and read the module on nutrition for people on dialysis (Module 9).

Portions of this article were reprinted from Fresenius Medical Care, California Dietetic Association and the National Kidney Foundation



STUDY USING DATA FROM GDCN ANCA PATIENTS PUBLISHED IN A NATIONAL JOURNAL

THANK YOU for your continued participation in the GDCN and for making this valuable research possible! We could not do it without you, and hope that you find this article summary interesting. Please contact us if you have any questions.

The full report is titled "Predictors of Relapse and Treatment Resistance in Antineutrophil Cytoplasmic Antibody-Associated Small-Vessel Vasculitis."

It is in the November 2005 issue of *Annals of Internal Medicine* (volume 143, pages 621-631). The authors are Susan L. Hogan, Ronald J. Falk, Hyunsook Chin, Jai Wei Cai, Caroline E. Jennette, J. Charles Jennette, and Patrick H. Nachman.

Relapse and Treatment Resistance in Patients with Small-Vessel Vasculitis : Patient Summary Article

What is the problem and what is known about it so far?

Vasculitis is blood vessel inflammation that develops when the immune system attacks the body. Inflamed blood vessels can decrease blood flow or cause small ruptures and bleeding into tissues. Several types of vasculitis primarily affect smaller blood vessels. Many of these types are associated with a kind of antibody called antineutrophil cytoplasmic antibody (ANCA). The condition commonly referred to as "ANCA-positive" small-vessel vasculitis most often affects the lung, sinuses, and kidneys. Doctors often treat patients with ANCA-positive small-vessel vasculitis with drugs that suppress the immune system. Most patients get better with treatment, but some do not. Some also relapse during or after treatment, meaning the disease and symptoms return and more treatment is usually required. Because of fear of relapse, doctors often give drugs to patients with small-vessel vasculitis for a long time. Giving the patients drugs for a longer time increases the risk for serious side effects. If doctors could identify which patients were more likely to relapse, they could treat them for a longer time and spare patients who are unlikely to relapse from potential side effects from long-term treatments.

Why did the researchers do this particular study?

To see which patients with ANCA-positive small-vessel vasculitis would respond to treatment and which would relapse.

Who was studied?

334 patients treated for ANCA-positive small-vessel vasculitis in the southeastern United States. Most patients had their disease diagnosed by kidney biopsy.

How was the study done?

The researchers studied patients with ANCA-positive small-vessel vasculitis, most of whom had kidney disease. Most patients were treated with corticosteroids plus an additional immunosuppressive drug. The researchers observed what happened to the patients over about 4 years. Patients whose kidney disease worsened or who had symptoms of vasculitis that never went away during treatment were considered resistant to treatment. Patients who initially improved with treatment but then worsened were considered to have relapsed. The researchers compared the patients by age, ethnicity, and other factors to identify features that predicted treatment resistance and relapse.

What did the researchers find?

About 1 of every 4 patients was resistant to treatment. Most patients who were resistant to treatment reached end-stage kidney disease, meaning they needed dialysis or a kidney transplant to survive. Treatment with corticosteroids only, without the benefit of another immunosuppressive drug, was strongly correlated to treatment resistance. Women, African-American patients, and those with severe kidney disease before treatment were more likely to be resistant. Of the patients who did respond to treatment, about 40% had a relapse. Patients who had lung disease, upper airway (sinus) disease, and a specific type of ANCA called proteinase 3 (PR3) ANCA were more likely to have a relapse than patients without these characteristics.

What were the limitations of the study?

Most of the patients had their vasculitis diagnosed by kidney biopsy. These patients may differ from patients with small-vessel vasculitis who do not have kidney disease or who do not undergo kidney biopsy. Also, the patients were cared for by different doctors whose treatment decisions differed. As a result, the researchers' findings might be the result of differences in doctors' treatment decisions or other factors the researchers were not able to measure.

What are the implications of the study?

Among patients with ANCA-positive small-vessel vasculitis, adequate treatment with corticosteroids and other immunosuppressive agents is important at diagnosis. Women, African-American patients, and patients with severe kidney disease may be less likely to respond to initial treatment. Among patients who respond to initial treatment, those with lung or sinus disease involvement and specific patterns of antibodies (PR3 ANCA) in the blood are more likely to relapse. These findings require confirmation, but they suggest that doctors may be able to reserve long-term treatment for some patients with small-vessel vasculitis, sparing others the side effects of prolonged exposure to immunosuppressive drugs.

The National Wegeners Granulomatosis Association (WGA) has changed its name to The Vasculitis Foundation

Founded 20 years ago and dedicated to patient support and the advancement of research, the **WGA** has renamed itself.

Now called **The Vasculitis Foundation**, the name was changed to capture the broader scope of the disease in order to increase awareness about, and funding for, research into vasculitis, including Wegeners Granulomatosis.

The 3,200-member group continues:

- * to fund research into the causes of vasculitis
- * to promote early diagnosis and improved treatment
- * to provide support for patients and families of those who have vasculitis
- * to conduct a biennial patient symposium (July 7-9, 2006 in Baltimore)
- * to conduct fund raising efforts

For more information on the Vasculitis Foundation, for membership info, or to find a local support group in your area, please call 1-800-277-9474 or go online at www.wgassociation.org

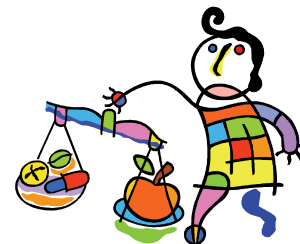
THE VASCULITIS SELF-MANAGEMENT STUDY

Help us understand how individuals living with vasculitis manage their condition! We are still seeking participants for the Vasculitis Self-Management Study. This is a research study for individuals who are living with vasculitis (or related conditions). We hope to learn more about the experiences that individuals with vasculitis have with carrying out the treatment plans suggested by their doctors. If you decide to participate, we will ask you to complete a survey that asks you about your feelings about your vasculitis and the tasks you perform to manage your illness. Participants will receive \$10 for completing the survey.

Do You Qualify?

You may qualify for this study if:

- You are over 18 years of age
- You have been diagnosed with a form of vasculitis, such as:
 - Wegener's Granulomatosis
 - ANCA Disease
 - Microscopic polyangiitis
 - Glomerulonephritis
 - Churg-Strauss syndrome
 - Several others (ask us if you are not sure!)



Please call us at 919-966-7538 or toll free at 1-866-827-2862 if you would like more information about this study. You may also email Carolyn Kalinowski Thorpe at ckalino@email.unc.edu. Your participation will help us better understand how individuals living with vasculitis manage their illness.

**You are the expert about the daily management of your condition,
and we want to learn from you!**

PARTNERS ADJUSTING TO ILLNESS RESEARCH STUDY (PAIRS)

The Thurston Arthritis Research Center at the University of North Carolina at Chapel Hill is conducting a research study specifically for couples living with lupus or vasculitis (and related conditions). The purpose of this study is to examine support and coping in married couples where one spouse has lupus or vasculitis. This study will examine the different ways couples communicate with one another, and how this might be related to coping with vasculitis. We hope to gain a better understanding of how communication and support affect coping when one spouse has a chronic condition like lupus or vasculitis.

Do You Qualify?

You may qualify for this study if:

- You are married; and
- You have been diagnosed with lupus OR a form of vasculitis, such as ANCA, Wegeners Granulomatosis, and Churg-Strauss (ask us if you are not sure!)

What Does the Study Involve?

In this study, couples will be asked to complete three sets of mailed surveys at home. They will also be asked to complete two separate in-person interviews. The interviews will be conducted at several locations, including UNC-Chapel Hill and other satellite offices across the southeastern United States (including select locations in VA, SC, & GA). Couples who complete the study will receive \$150 for their participation.

To Find out more:

If you would like more information about this study, please contact Lesha Miller, Project Director, at (919) 843-9256, or toll-free at (866) 827-2862 (please ask for the PAIRS coordinator), or via email at: dlmiller@email.unc.edu.

FSGS CLINICAL TRIAL

The Focal Segmental Glomerulosclerosis Clinical Trial is a multi-center, randomized trial to compare the effectiveness of 2 treatment regimens in patients with steroid resistant idiopathic FSGS. FSGS is a kidney disease that causes scarring of the filters (glomeruli) in the kidney, allowing protein to leak into the urine. If left untreated, FSGS can lead to end stage renal disease (ESRD).

This trial will help determine the effect of two therapies on kidney function in patients with FSGS and any side effects associated with the two treatments. One therapy involves a drug called cyclosporine A (CYA). CYA has been used for kidney transplant patients for adults and children for many years. It has also been used to treat patients with FSGS. The other treatment consists of a drug called mycophenolate mofetil (MMF) and intermittent doses of a steroid, dexamethasone. MMF has also been used in transplant patients. The use of cyclosporine, dexamethasone and MMF has been reported in small numbers of patients with FSGS, but the drugs have not been compared to each other in a large trial such as this.

The trial will enroll children and adults ages 2-40 years and is sponsored by the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases. For more information, please call Leslie Powell at 1-866-462-9371, or by e-mail: leslie_powell@med.unc.edu. You can also check out the national website: www.fsgstrial.org.

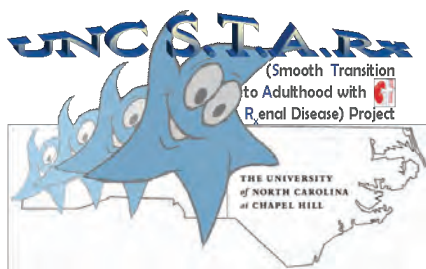


This study is being conducted to learn more about how chronic kidney disease (CKD) affects children. CKD happens when the kidneys have trouble removing waste products from the blood. The number of people with CKD continues to grow, and about 650,000 Americans will have CKD by the year 2010. Although doctors have studied CKD in adults, there haven't been many studies that look at CKD in children.

Unfortunately, not all information from adult studies can be used to help children, since children develop CKD for different reasons than adults do. In order to treat the problems caused by CKD in children, it is necessary to understand the process of CKD in children. The goals of this study are to look at the factors that cause CKD to change in children, and to see how CKD affects brain development, behavior, heart function, growth and general well-being.

Your child's participation in this study will last for approximately three years. There will be one study visit per year except during the first year when there will be two study visits.

The study will enroll 540 children, ages 1-16, $GFR \leq 70$, at 57 medical centers, including UNC Hospitals. For more information, please call Leslie Powell at 1-866-462-9371, or by e-mail: leslie_powell@med.unc.edu.



The purpose of the UNC Smooth Transition to Adulthood with Renal Disease (STARx) Project is to address transition to adulthood in adolescents with chronic kidney disease (CKD) and end-stage kidney disease (ESKD). Investigators will be holding focus groups across the state to learn from adolescents and young adults, parents, and health care providers about the challenges and experiences of transitioning through life with a chronic disease. These focus groups will help the investigators develop a "transition readiness survey" to use with patients and their families. For more information on this study, please contact Caroline Jennette at caroline_jennette@med.unc.edu or by calling toll-free, 1-866-462-9371.

LUPUS STUDIES UPDATE

There are now 5 treatment trials for lupus underway at UNC. These studies include patients with lupus who have new or recurrent lupus nephritis, resistant nephritis and severe lupus that does not affect the kidneys. For more details and a full list of inclusion/exclusion criteria, please contact Brenda Meier, Lupus Clinical Trials 919-843-6619 or beeper 919-216-1185. You may also call the GDCN toll-free line at 1-866-462-9371.

1. If you have **New or Recurrent Nephritis**, you **MAY** be eligible for the **Aspreva Lupus Management Study (ALMS)**. This is a 2 year treatment study evaluating **6 months of intravenous cyclophosphamide versus mycophenolate mofetil (MMF)** for induction. This treatment is then followed by **2 to 3 years of MMF or azathiaprine**. Although patients are not paid for being in the study, drugs are covered for the patient. To be eligible for this study, you must be between 18 and 75 years of age and have active lupus nephritis, either new or recurring. Only your doctor or one of the UNC doctors can determine if you are medically eligible for this study. If you are interested in more information about the study, please call contact Brenda Meier, Lupus Clinical Trials 919-843-6619 or beeper 919-216-1185. She can answer questions about the study and help determine if you can be further evaluated for participation in the study.
2. If you have lupus **nephritis that is not responding to treatment**, you may be eligible for a treatment trial that will test the use of **rituximab or a placebo (sugar pill), in combination with mycophenolate mofetil**. To be eligible for this study, you must have lupus nephritis and be between the ages of 18 and 75. Only your doctor or one of the UNC doctors can determine if you are medically eligible for this study. If you are interested in more information about the study, please call contact Brenda Meier, Lupus Clinical Trials, at 919-843-6619 or beeper 919-216-1185. She can answer questions about the study and help determine if you can be further evaluated for participation in the study.
3. If you have **severe symptoms of lupus without lupus nephritis**, then you may be eligible for another study of **rituximab compared with placebo (sugar pill)**. As with the above two studies, you must be between the ages of 18 and 75 and only your doctor or a UNC doctor can determine if you meet the entry criteria for the study. Please call Brenda Meier, Lupus Clinical Trials 919-843-6619 or beeper 919-216-1185 to learn more about this study.



There are also two **Phase I trials** for people who have lupus. Phase I trials are used for studies of NEW drugs in a small group of patients. Phase I studies may evaluate, for example, the best way to give a new treatment (by mouth, intravenous infusion, or injection), the best dose to use, or for evidence of a benefit or harm from using the treatment being studied. Because little is known about the possible risks and benefits of the treatments being tested, Phase I trials usually include only a small number of study volunteers who are likely to be helped by the drug. These studies are very important and often lead to much bigger studies for many more patients.

4. One of the current Phase I studies will evaluate the safety of a **single dose of CTLA4-IgG4m (RG2077)** in **patients with active lupus who are already being treated with cyclophosphamide**.
5. The other Phase I study will test the use of **edratide in subjects with mild to moderate symptoms of lupus**. Edratide is a novel protein developed from a double stranded-DNA antibody administered subcutaneously. This study will evaluate a once-a-week administration of three doses of edratide on overall disease activity in lupus patients and will be compared to a placebo (an injection that has no medication).

There is also a long-term **cohort study** that is enrolling patients with lupus. The study is called the **Systemic Lupus International Collaborating Clinics Registry for Atherosclerosis (The SLICC Study)**. SLICC is a group of rheumatologists from 25 international centers who have been working collaboratively to carry out research in lupus. This group has been recruiting to an international registry of patients to look at the important area of heart disease and nervous system involvement in lupus. This study will allow researchers to determine the prevalence and nature of early atherosclerotic coronary artery disease, identify associated risk factors, and gain important insight into the prevalence, causes and management of coronary artery disease in lupus. Through the UNC Division of Rheumatology and the Glomerular Disease Collaborative Network, Dr. Mary Anne Dooley and Brenda Meier, RN have recruited 25 subjects in this study. **More patients are needed, so please consider learning more about this study by calling Brenda Meier** at 919-843-6619 or beeper 919-216-1185.

If you are enrolled in this study, you will be followed for certain medical and laboratory measures over at least 18 months and possibly longer depending how long the study goes on. You are NOT given a specific study medication (and are not asked to discontinue any regular medications taken for lupus or other conditions). The purpose of this study is to assess the risk of cardiovascular disease in patients diagnosed with lupus. Once a year, blood is drawn (to look for genetic markers) and a questionnaire is completed. Each patient in the study will receive a free electrocardiogram (EKG) and there is no charge for laboratory measures or study visits with the rheumatologist.

HELP YOUR FAMILY PREVENT KIDNEY FAILURE

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.

Why should my family know about kidney disease?

Kidney disease runs in families. Even if only one person in a family has kidney failure, all blood relatives should be tested for kidney disease. With early treatment, kidney disease can be slowed and dialysis or transplant may be avoided.

What should I tell my family about kidney disease?

Tell your family that:

- Diabetes and high blood pressure are the leading causes of kidney failure.
- Control of blood sugar and blood pressure may help the kidneys stay healthy.
- They should get tested for kidney disease because it runs in families.



How can I help my family prevent kidney failure?

Tell your family members to talk to their doctors about getting tested for kidney disease.

What should my family members ask their doctors?

Tell your family members to ask their doctors to test their blood and urine for kidney damage. These tests are the only way to find out if they have kidney disease because there may not be specific symptoms. Finding kidney disease early and treating it can slow kidney damage and may prevent kidney failure.

Where can I get more information?

For more information about kidney disease, contact the National Kidney Disease Education Program at 1-866-454-3639 or www.nkdep.nih.gov.

RECIPE BOX: MACARONI SALAD

Diet type: CKD non-dialysis Dialysis Diabetes

Servings: 16

Serving Size: 1/2 cup

Ingredients:

- 3 cups cooked macaroni
- 1/4 cup pimentos
- 1/2 cup onion (chopped)
- 1/2 cup green peppers (chopped)
- 3 hard boiled, shelled eggs (chopped)
- 1/2 cup mayonnaise
- 1/2 cup celery (chopped)
- 1 teaspoon mustard (regular dry)
- paprika (sprinkle)
- black pepper (sprinkle)

Preparation:

1. Cook macaroni, rinse under cold water and drain well.
2. Combine all ingredients: macaroni, pimentos, onions, green pepper, eggs, mayonnaise, celery and mustard. Mix well.
3. Sprinkle with paprika and black pepper.
4. Chill and serve.

Suggestions: May omit mayonnaise and use oil and vinegar to lower sodium. May omit onions or celery and add green peas, cucumbers or parsley.

Nutrients per serving:

Calories 111
 Protein 4 g
 Fat 4 g
 Cholesterol 53 mg
 Sodium 78 mg
 Potassium 97 mg
 Phosphorus 53 mg

Dialysis, Diabetic Dialysis, and pre-dialysis food choices:

1 starch
 1 fat



Always consult with your physician, dietitian and other members of your dialysis team before partaking in any activity or trying any recipe.

Visit www.DaVita.com to find more recipes and information on kidney disease

DEPRESSION AND CHRONIC KIDNEY DISEASE

Clinical Depression is a common problem for many patients with kidney disease. Unfortunately, depression often goes undetected and untreated. Many patients tell me:

- “ I don’t know what’s wrong. I just can’t seem to get it together.”
- “ I cry a lot. I don’t even know why.”
- “ I’m normally a lot stronger than this.”
- “ I just don’t want to do anything. I sit around the house all day.”
- “ I can’t focus on my work and I’m snapping at everyone around me.”
- “ My friends ask me out, and I just don’t want to go out anymore.”
- “ I have no interest in sex anymore. I don’t know what’s happened to me.”
- “ I feel tired all the time. I go to bed tired, and I just can’t sleep.”
- “ I’m just so sad all the time.”
- “ Nothing ever seems to get better.”
- “ I thought I would be happy after my kidney transplant”



Do any of these comments sound familiar? These are frequent comments from patients who are depressed. Depression is more than just feeling low. Depression is a clinical condition that causes tremendous changes in both thought processes and physical symptoms. Depression results from chemical changes in the brain that may occur in association with other physical illness, emotional trauma from severe situational changes or losses, hormonal imbalances, medications, and a whole host of other causes. Depression is common in patients who have kidney disease regardless of whether they require medication, dialysis, transplantation, or none of these. It may be present in both adults and children.

Patients with kidney disease are prone to depression for a number of reasons. Loss of good health is devastating and some patients just don’t adjust to the diagnosis and treatment as easily as others. If declining health is accompanied by financial losses due to cost of health care and declining ability to work, the psychological burden becomes even greater. Often, a patient’s identity is tied to their ability to be a provider for their family. Loss of employment or simply a decrease in ability to focus on work can be very overwhelming. Some patients see themselves as the “strong one” in the family, and kidney disease may cause them to feel “weak or useless,” even if they are still working. Patients may feel that their role in the family has changed because they require help with getting to and from treatments, taking care of children, or doing housework. Accepting a diagnosis of kidney disease is difficult enough, but often the other changes that come with the diagnosis, such as financial hardship, role changes in the family, loss or changes in employment and fear of what the future brings can contribute to depression.

Symptoms of depression are sometimes tricky to recognize in patients with kidney disease, because some of the symptoms of End Stage Renal Disease (the need for dialysis) can also be symptoms of depression. Changes in memory, energy level, ability to focus, concentrate, do simple calculations, and a general sense of being in a fog can all be symptoms of worsening kidney disease, and /or depression. However, depression brings with it another layer of symptoms. These symptoms have to do with lack of joy in one’s life, lack of motivation to do the things one normally enjoys, a sense of hopelessness, social withdrawal, and in its most severe form, a sense that life is not worth living. Depression also causes changes in appetite, whether under or overeating. Sleep disturbances in depressed patients may be characterized by sleeping all the time or inability to sleep. Decreased or lack of interest in sex is a very common symptom of depression as well. Some patients will have all, or just one or two of these symptoms. The most important ideas to understand about depression are that:

Depression is very common and very treatable. You can and will feel better, even if you can’t see the light at the end of the tunnel right now.

Treatment can consist of medication, talking with a therapist, or both. Length of therapy is different for everyone.

Treatment does not have to be extremely expensive. There are local or county resources that may help such as the mental health division of county health departments, clinical social workers or psychiatric nurse practitioners that are trained in the treatment of depression, and psychologists or psychiatrists who provide care on a sliding scale basis.

The best place to start if you think you may be suffering from depression is to tell your physician or nurse. They will help you find treatment. Depression robs patients of energy, joy, sleep, and causes physical discomfort. Having kidney disease doesn’t mean you have to be constantly sad or stop enjoying life. Treatment of depression can allow you to go forward, enjoy life and find joy again. Please tell your health care team if you think you are depressed and need help.

Clara Neyhart, RN, BSN, CNN
Nephrology Nurse Clinician
Division of Nephrology and Hypertension
UNC Kidney Center

National Resources for referrals and information:

National Mental Health Association: 1-800-969-6642 (www.nmha.org)

Families for Depression Awareness: 1-781-890-0220 (www.familyaware.org)

National Association of Social Workers: 1-202-408-8600 (www.helpstartshere.org)

NATIONAL NEPHROTIC SYNDROME & FSGS CONFERENCE FOR
PARENTS, ADULT PATIENTS, FAMILIES AND FRIENDS
JUNE 3-4, 2006, PHILADELPHIA, PA

NephCure is joining forces with the Children's Hospital of Philadelphia for the premiere National Nephrotic Syndrome and FSGS Conference in Philadelphia, PA. Dr. Bernard Kaplan, chief of the Division of Nephrology at Children's Hospital, will chair this conference, which will offer **pediatric and adult** patients and their families and friends the opportunity to learn more about the conditions, treatments, research and the effort to find a cause and cure for nephritic syndrome and focal segmental glomerulosclerosis (FSGS).

Planned topics include:

- Research Updates
- Contacting/Influencing Your Congressman
- Insurance/Medicare/Medicaid/Social Security
- Renal Diet
- Raising a Child with Chronic Kidney Disease
- Treatments for nephrotic syndrome and FSGS
- Fundraising for Research
- Plus the chance to interact with other patients and their families!



If you are interested in attending and would like to receive a registration kit, please e-mail Kevin Tierney at ktierney@nephcure.org or call 1-866-NEPHCURE. The registration fee is \$125 per person.

NephCure is offering a limited number of **scholarships** to the Conference for patients and/or families that require financial assistance. For more information on this program, please contact Kevin Tierney.

The NephCure Foundation is the only organization solely committed to seeking a cause and cure for two potentially devastating kidney conditions, Nephrotic Syndrome and Focal Segmental Glomerulosclerosis (FSGS). NephCure is made up of patients, their families and friends, researchers, physicians and other healthcare professionals joining forces to create awareness and generate funding for research.
Website: www.nephcure.org

SUMMER CAMPS FOR KIDNEY PATIENTS

Summer camp is a great way for kidney patients to get some fresh air, connect with peers who are also living with chronic diseases, and be under the supervision of certified nurses and physicians.

The **National Kidney Foundation** (NKF)'s Patient and Family Council has an online listing of camps that accept kidney patients by state. This directory can be accessed by going online: http://www.kidney.org/patients/pfc/kidney_camp/index.cfm or by calling the NKF toll-free at 1-800-622-9010.



The **Victory Junction Camp**, located in Randleman, North Carolina, serves children with chronic diseases in North Carolina, South Carolina, and Virginia. The Victory Junction Gang Camp is about fueling ill children with memories that will sustain and inspire them! For the children, it's as simple as kicking back and relaxing, making friends with other children who have illnesses, not worrying about being different, experiencing the fun and activities of summer camp and making memories.

June 18-23, 2006 is the week of Victory Junction Camp devoted to children with heart, lung, and kidney diseases. For more information, or to fill out an application, visit www.victoryjunction.org, or call 1-336-498-9055 and ask to speak with Angie Campbell or Whitney Doel. This camp is provided free of charge to campers, and serves children ages 7-15.

The Kidney Coaching Foundation

NEW ORGANIZATION FOR ADOLESCENTS AND YOUNG ADULTS WITH KIDNEY DISEASE

The Kidney Coaching Foundation (KCF) is a not-for-profit organization that delivers life coaching and personal development programs to adolescent and young adults ages 12-21 who have kidney disease. The KCF's goal is to provide each member of their program with a trained volunteer coach who guides them in acquiring the tools necessary to comply with their medical treatment, and also helps them to navigate the dual complexities and challenges of life as a young adult experiencing the effects of life with kidney disease. The KCF's purpose is to inspire, motivate, and encourage their youth that it is possible to live a productive and successful life with renal disease. It is their long-term vision to support kidney patients and their families, not only in the North Carolina area, but across the United States.

For patients they:

- Help to set realistic goals to help them become more compliant
- Encourage and inspire them to keep themselves healthy
- Mentor one on one and build a relationship with them that will last a life time

Deidra Hall, founder of the Kidney Coaching Foundation, understands firsthand the issues facing the young kidney patient. She was one.

For parents they:

- Encourage them to take a more active role in their child's health care
- Offer programs and networking opportunities with other parents who are in the program.
- Will be an extra support during hospital stays to give the parent some "relief" time to take care of themselves
- Translation services for families of Hispanic descent (if you can translate in another language please consider being a volunteer with us).

The KCF is launching their program soon and are looking for volunteer coaches, and will be starting to see patients by Fall 2006. For more information, or to apply, please go to www.thekcf.org. You may also write to them at: The Kidney Coaching Foundation, PO Box 41272, Raleigh, NC 27629.



WeKan is part of The Renal Support Network (RSN), an organization founded by Lori Hartwell. Lori's knowledge of kidney care and treatment is based on experience – she has lived with renal disease for over 30 years.

The RSN's mission is to meet the non-medical needs of those living with kidney disease. The RSN works to make sure kidney patients have access to the best healthcare and employment resources possible.

WeKAN Patient Activists work to empower fellow patients to make informed decisions about their care, to become involved in policies that impact their life and to speak up. By educating patients on how to become actively involved in decisions affecting their lives, weKAN promotes self-advocacy and self-determination.

In 1965, there were committees that literally chose who was "worthy of saving" from Renal Disease. The equipment was very expensive and treatment was not covered by the government. For many thousands, kidney disease was a death sentence. Only after a lot of advocacy and actually dialyzing a patient before Congress, did the country attain a special provision for government (Medicare) reimbursement in 1972. The nation's health care system is undergoing a series of swift and major changes. Legislators need to hear from people who have chronic kidney disease.

WeKAN Patient Activists are already making a difference. They are getting to know their elected officials and educating them about kidney disease and what patients need to ensure quality care. WeKan is planning patient education meetings around the country as well as being invited to participate as speakers. In addition, there are many "behind the scenes" committees that make decisions about kidney patients' care. Several weKAN Patient Activists are participating on some of these committees and providing the patient's perspective. It is weKAN's goal to help patients - help patients.

WeKAN is a small group of Patient Activists with big ideas! Their wish is to inspire you and give you the tools that will help you make a difference in your community. An illness is too demanding when you don't have hope.

For more information or to join the Renal Support Network, call 818-543-0896 or register online at <http://www.renalnetwork.org/pages/membership.php>

A number of WeKAN patient leaders will be traveling to Washington, D.C. this summer to talk to legislators about the **Kidney Care Quality and Improvement Act of 2005**. Please see the next page for more information on this bill and how you can help by contacting your own legislators.

PATIENT ADVOCACY:

TAKE ACTION AND HELP SUPPORT BILLS FOR KIDNEY PATIENTS

In the fight for health awareness and disease prevention, it is important and empowering for patients to get involved in political decisions that may affect them and the future of their disease. Kidney patients know, like no other person can, the challenges and triumphs of living with kidney disease. Your local, state, and national representatives are accountable to you and are available to listen to your thoughts, ideas, and concerns. For more info, please check out the patient advocacy page at <http://unckidneycenter.org/patientadvocacy.htm> or call Caroline toll-free at 1-866-462-9371.

Senate Bill 635/House Bill 1298: Kidney Care Quality and Improvement Act of 2005

This expansive bill is separated into 4 main sections. For the full text of this bill, go to <http://thomas.loc.gov>, or contact Caroline at the number above for a mailed or e-mailed copy.

Important elements of this bill for kidney patients and citizens:

- Providing financial incentives for dialysis centers and providers who demonstrate improved quality of care.
- Creating a better training program for dialysis technicians.
- Providing money for educational programs that could help prevent people from developing kidney failure, or at least delay its onset.
- Increasing the reimbursement rate for dialysis facilities to help decrease employee turnover and ensure that clinic will not have to close down due to financial problems.
- The bill would remove some of the financial barriers to providing dialysis in the patient's home. Home dialysis (specifically, home hemodialysis) has been shown to result in improved patient outcomes.
- Medicare coverage of educational programs for kidney patients who will require dialysis and/or transplantation, so that patients can learn about ALL of the different treatment modalities for end-stage kidney disease so they can choose the one that is best for them.

Sample Letter to congressman:

Dear Congressman/Senator [NAME]:

As a resident of [STATE/YOUR DISTRICT], and a [DOCTOR/NURSE/PATIENT WITH KIDNEY FAILURE], I would like to urge you to support the Kidney Care Quality and Improvement Act of 2005 (HB 1298/SB 635).

Nationally, more than 400,000 Americans suffer from kidney failure, or end-stage renal disease (ESRD) and of those, 75 percent rely on Medicare for their dialysis treatments. Dialysis is not an "optional" treatment for [US/THESE INDIVIDUALS]. Without daily dialysis treatments to remove toxins from the blood, patients with kidney failure cannot survive. It is truly a lifesaving therapy, and a medical necessity for many of your constituents.

Patients with diabetes, obesity and hypertension are increasingly suffering from kidney failure, and a great majority rely on Medicare to pay for their care. Clearly, there is a growing need to educate patients about the risk factors for kidney failure, and to ensure quality care remains available for those who are unable to avoid it.

At the current rate, the number of Americans with kidney failure is expected to quadruple in the next 25 years. Unfortunately, Medicare is not equipped to handle such huge numbers of patients who need dialysis to stay alive.

Fortunately, there is a solution. There is a bill before Congress that aims to help this program. The Kidney Care Quality and Improvement Act improves funding for dialysis and ensures that future generations of Americans will have the care they need. This bill also has an important education component that will help teach Americans about how to steer away from lifestyles that can result in the loss of kidney function, or better maintain their lifestyles during dialysis treatment.

Please consider supporting the Kidney Care Quality and Improvement Act. The quality of my life and many others depends on it.

Sincerely... Name/Address



*Want to contact your State
Representatives and urge
support for
SB635/HB1298?*

On the web:

<http://www.house.gov>

<http://www.senate.gov>

<http://www.statelocalgov.net>

By Phone: 1(800) 333-4636

Use these resources to find out who represents you and how to contact them. If you need help locating your representative, leave a message on the GDCN patient line with your name, address, and telephone number and Caroline will let you know who they are : 1-877-462-9371

Caroline can also give you resources if you would like to write a letter to the editor of your local newspaper, or you can find info and links online at:

www.unckidneycenter.org/patientadvocacy.htm

RESOURCE PAGE

Kidney School

Website: www.kidneyschool.org

Kidney School is an interactive, web-based learning program in 20-minute modules. It was designed to help people learn what they need to know to understand kidney disease and its treatment, adjust to kidney disease, make good medical choices, and live as fully as possible. You decide which modules to visit and when—so what you learn is entirely up to you.

American Association of Kidney Patients

Phone: 1-800-749-2257

Website: www.aakp.org

E-mail: info@aakp.org

The AAKP is the only national kidney patient organization directed by kidney patients for kidney patients. Services include a patient magazine, an online newsletter, and patient support and education.

KidneyDrugCoverage.org

Phone: 1-800-622-9010

Website: www.kidneydrugcoverage.org

E-mail: info@kidneydrugcoverage.org

The Kidney Medicare Drugs Awareness and Education Initiative is a service of the kidney community, designed to provide timely, consistent, reliable, and up-to-date information about Medicare and Medicare Prescription Drug Coverage (Part D).

KIDney Kids Resource Ring

Website: <http://k.webring.com/hub?ring=kkrr>

KIDney KID'S RESOURCE RING is a resource, support, and dedication listing for parents who have children with kidney disease. It contains sites with info on numerous diseases that afflict children, places to go for support: including listserv groups, and pages dedicated to children with kidney disease.

The transAction Council

Phone: 1-800-622-9010

Website: www.transplantrecipients.org

E-mail: transactioncouncil@kidney.org.

The transaction council was created for kidney patients either awaiting or who have received a kidney transplant. The mission of the organization is to improve the quality of life for transplant patients, promoting donor awareness, and giving transplant patients a chance to share stories, experiences, and resources.

The American Kidney Fund

Helpline: 1-800-638-8299

1-866-300-2900 (Spanish)

Website: www.akfinc.org

E-mail: helpline@kidneyfund.org

The American Kidney Fund was founded in 1971 and has since become the nation's leading non-governmental source of direct financial assistance for needy kidney patients. Each year, AKF helps thousands of dialysis and transplant patients pay for treatment necessities.

Patient Advocate Foundation

Phone: 1-800-532-5274

Website: www.patientadvocate.org

E-mail: help@patientadvocate.org

The Patient Advocate Foundation is a national non-profit organization that seeks to safeguard patients, including those with kidney disease, through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.

Lupus Foundation of America

Phone: 1-800-558-0121

Website: www.lupus.org

E-mail: info@lupus.org

The Lupus Foundation of America (LFA) is dedicated to finding the causes and cure for Lupus. Research, education, and patient services are at the heart of LFA's programs.

A Newsletter from the
Glomerular Disease
Collaborative Network

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

Phone: 919-966-2561
Toll-Free: 1-866-462-9371
Fax: 919-966-4251
Email: gdcnunc@med.unc.edu



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



www.unckidneycenter.org



For more kidney disease information,
internet links, and printable copies of
this newsletter, check out
our website:
www.unckidneycenter.org