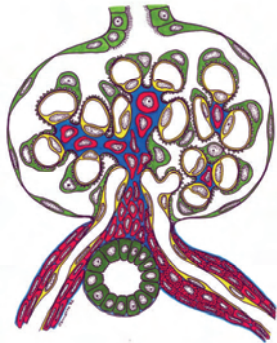


# KIDNEY CARE



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

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## TWO KEYS THAT OPENED THE DOOR TO MY LIFE

By Deidra Hall

As I lay in the hospital bed, a foreign place for me, I looked around. My face and body were not the same as they had been a few months ago. Now my eyes and face were swollen beyond recognition. Out of curiosity, I found myself pressing on my legs to see how long it would take the indentation to leave. The steady sound of the beeping IV was annoying yet the rhythm was comforting. Already I'd missed about three weeks of school, and I'm missing my friends. Would this be my life forever?

At that point I decided I would not live like this and I would do whatever it took to get back to normal – life was going on, and I wanted to be an active participant! Of course I could have sat around, lived in fear and had a woe-is-me attitude. Besides, I was a teenager and had the right to be a little moody! But I had to get back to my life. I had to have faith that things would get better.

So let's talk a little bit about faith. Faith is an effective way of living; *deciding* to have a positive attitude coupled with hope, which will bring us to a positive outlook on life.

We exercise our faith every day without knowing – from sitting down in a chair, to going to dialysis. We have no certainty these things will work – but we operate on the hope that they will. Surely when we sit on a chair we do not carefully test it out. We do not put weights equaling our body mass in it first to see if it will hold up. No – we just sit. We are putting confidence in that chair without knowing the results. If that chair brakes while we sit in it – does that stop us from finding another chair? No, we sit!

In every stage of my sickness, I needed faith. If one treatment didn't work, I couldn't just throw in the towel, I had to take on what was next. I had to have faith that the medications I'd never taken before would work. I needed to have the faith that the machine taking the blood out and returning it to my body would keep me going a little bit longer. Finally, I needed to have the faith that the transplant I would receive would not only work, but last.

Fear was not an option. Why? Because fear overrides faith. If we look at the definition, faith is the confidence that what we hope for will actually happen; it gives us assurance about things we cannot see. If I had any amount of fear it would have automatically overridden any confidence I had, thereby negating my faith.

Doubt was not an option. If I as going to have faith, I had to be fully persuaded and committed in my mind that things would work out. To doubt would be to worry about things beyond my control. No matter how close I followed doctors' orders, I couldn't control the test results I would get that next day. I couldn't control whether the surgery for the PD catheter would work the second time around. But in my mind, I had to be fully persuaded that they would.



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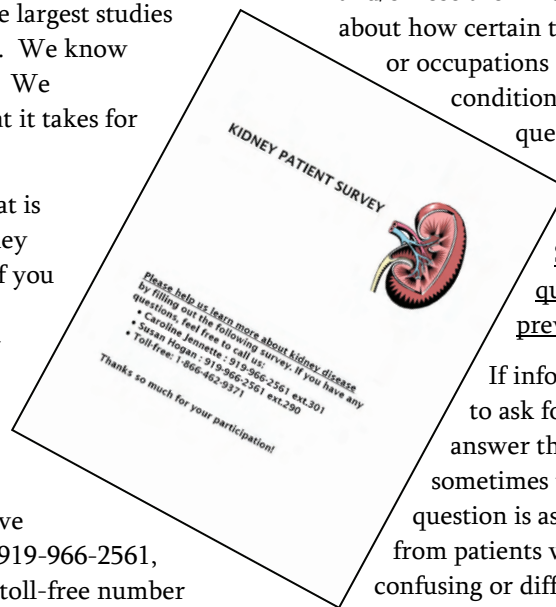
Lupus Clinical Trials Fund  
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## WHY SO MANY QUESTIONS?!

### THE IMPORTANCE OF KIDNEY PATIENT QUESTIONNAIRES

For certain studies, we mail questionnaires to patients with kidney disease. It is always important that we collect the completed questionnaires from as many patients as possible. Your answers contribute to our understanding of kidney diseases in several ways. Most frequently, information collected from questionnaires is used to help us understand factors that may either contribute to developing kidney disease or that could influence your health once you have kidney disease. In fact, by participating and completing the questionnaires, you will contribute to some of the largest studies ever done on glomerular diseases. We know these questionnaires can be long. We appreciate the time and effort that it takes for you to fill them out!

A picture of the questionnaire that is currently being mailed, the 'Kidney Patient Survey', is shown here. If you have received one of these questionnaires, or receive this or any others in the future, PLEASE participate by filling in your answers as best as possible and returning it to us in the postage-paid envelope. If you have questions, please call Caroline at 919-966-2561, ext 301 or leave a message at our toll-free number 1-866-462-9371 and we will return your call.



Some of the most commonly asked questions we get about the questionnaires are included below, followed by our response.

#### **Common Questions and Our Responses:**

##### Why is it important to complete these questionnaires?

The information we ask in the questionnaires is usually about things that are difficult to find or not a part of your medical record. The items we ask about may include, for example, the types of jobs you've worked in, your other medical problems, certain medicines you have taken, if and how much you have smoked, and types of infections and immunizations you have had. Getting the information directly from you is the only way we have to gather this type information, and allows us to learn more about what contributed to your having kidney problems in the first place. There are very few studies of this type, especially for many of the specific kidney diseases.

##### How will completing the questionnaire benefit me?

For the most part, there will not be a direct benefit to you. However, if we can learn more about what causes these kidney diseases then your participation may help keep others from getting the disease. In addition to learning about potential causes of disease, we can also use the questionnaire information to learn more about why some people have very few ongoing symptoms of their kidney disease while others struggle regularly with symptoms and/or lose their kidney function. If we can learn more about how certain things such as environmental exposures or occupations (jobs), stress and other medical conditions influence kidney function, these questionnaire studies may have an impact on how your disease is managed in the future.

##### Sometimes it seems like the same questions are in questionnaires I have previously completed. Why?

If information is important, it is better for us to ask for it twice and be sure we get an answer than to not have it answered. Also, sometimes there are small differences in the way a question is asked. Wording changes may result from patients who let us know that a question was confusing or difficult to answer. Please feel free to share questions or comments with us by either calling or writing something right on the questionnaire!

##### The questionnaires sometime ask me to remember things that happened during a certain time before I was diagnosed. What if I am not sure I remember all of the details?

We want the most accurate answer possible, but there are no right or wrong answers. Spend some time thinking about the BEST answer to the question. Sometimes this means thinking about it for a few hours or days or talking with someone who was close to you during that time to help you remember.

##### What if there are certain questions that I do not want to answer?

Although we hope that you will answer all of the questions, you are free to skip any questions you do not want to answer. Any answers that you decide to provide will still be helpful to our research.

*Continued on Page 6...*

## ADVOCACY IN ACTION: "WEKAN" PATIENT GROUP MEETS UNITED STATES LEGISLATORS

by Beth Holloman, Patient Advocate

On June 3-5, 2007, 31 members of weKAN, The Wellness Education Kidney Advocacy Network, a program of the Renal Support Network, met in Washington, DC to discuss the Kidney Care and Quality Education Act of 2007 (KCQEA) with US legislators. Our 31 member group met with a total of 169 legislators over the three day period. We represented twenty-nine states in an effort to educate our elected officials about kidney disease and the KCQEA of 2007. The acronym "HEART" best describes the main points of this legislation and what we were trying to share with our legislators:



**H= Home Dialysis:** seeking to understand the barriers to the adoption of different treatment modalities by patients.

**E=Education:** providing educational sessions for Medicare beneficiaries with Stage 4 Chronic Kidney Disease (CKD) to teach them how to slow the progression of the disease.

**A=Awareness:** creating public and patient education initiatives to increase awareness about CKD and to help patients learn self-management skills that prevent and control CKD.

**R=Reimbursement:** establishing a three-year Continuous Quality Improvement Initiative that would reward providers for quality improvement and outcomes.

**T=Technicians:** establishing a uniform training for patient-care dialysis technicians.

I was fortunate enough to be selected to go to Washington to represent North Carolina, and I was able to meet with 7 North Carolina Representatives and Senators, and/or their healthcare legislative aides over this three day period.

Our experience began with a "get to know each other" dinner on Sunday night and a full day of training on Monday. Tuesday, we "Hit the Hill" as 31 of us descended upon Capitol Hill to meet with our legislators. Our goal was to educate our legislators about the importance of the Kidney Care and Quality Education Act of 2007 from a patient's point of view. Often, lobbyists, doctors, and nursing associations meet with legislators, but it is rare for a group of volunteer patient advocates living with the disease to go to Washington to meet with legislators. Our visit made a huge impact on the legislators, and we came away with many more co-sponsors for the legislation than we had when we arrived. Additionally, we learned from each other how to live with kidney disease and made friends with our fellow members, many of whom had never met each other.

You too can make a difference! If you would like to voice your opinion about this legislation or learn more, please visit the Renal Support Network's site at <http://www.rsnhope.org>. Click on the advocacy link in the menu to the left and get involved! Together, we really can make a difference!

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### TWO KEYS Cont...

So how did I increase my faith? Glad you asked!



- **First – I got some understanding.** The more you understand, the less likely you are to be afraid. I had to understand my enemy – the disease, and had to know how to go to war with it. I also had to understand that it is the disease I had to fight, not my loved ones and the health care professionals trying to help me.
- **Second – I thought positive thoughts.** Negativity increases worry and doubt!
- **Third – I had a vision and a destination!** I saw myself doing great things in the future. I saw my husband and children. I saw my professional life. I saw the vacations I would take. I gave myself a reason to live. No vision, no hope. No hope, no reason to live. No reason to live....well you know the rest.

So I encourage you – if you just found out, or have been living with CKD for years, fear not. This is NOT the end - get some faith because you have a reason to live!

*Deidra Hall is a transplant recipient of 13 years, wife, mother of two and founder of The Kidney Coaching Foundation, Inc.*

*Website: [www.thekcf.org](http://www.thekcf.org)*

## SO YOU THINK YOU MAY NEED/WANT A KIDNEY TRANSPLANT?

*By David Cole, Transplant Recipient*

### **So you think you may need a kidney transplant?**

I've had the opportunity to meet with several people over the past few months who were facing the prospect of end stage kidney disease and a likely kidney transplant. I was able to share with them my own experiences as a transplant recipient. Here are some of the encouragements, and cautions, I offered:

### **You're going to feel WAY better!**

Kidney disease is usually a slow process, and you get gradually sicker over time. With the transplant, barring any major complications, you'll start feeling better almost immediately. In my own case, even though I was recovering from major surgery, I felt better two days after the transplant than I did before, and it just got better from there. Of course there are some transplant recipients who do not have normal kidney function right away. It may take days or weeks, but most of these folks also feel considerably better within a short time.

### **Your life will probably return mostly to normal.**

I realize everyone's circumstances are different, but you will feel better, you'll be more energetic since you'll likely be less anemic, if at all, and you probably won't have any kidney diet restrictions (other than avoiding uncooked foods). My transplant allowed me to return to work full time and resume an active lifestyle that includes cycling and kayaking.

### **Your transplant won't be visible.**

I wasn't aware until just a few months beforehand that with a kidney transplant, the original kidneys are not usually removed. The new kidney is "plumbed" into the body in the front, usually on the lower right side. In my case, once the incision healed, it really wasn't detectable that I had a transplant. Unlike liver, lung, and heart transplants, the incision is small and out of the way.

### **Your sex life shouldn't be affected.**

This is one of those topics that is hugely important to patients and their partner, but that you rarely see addressed in the literature, other than, "Discuss with your doctor." Don't be afraid to talk with your doctor, particularly about any unwanted side effects of your medications. Hypertension medications, in particular, can be problematic in this regard for men.

### **You may have to return to the hospital.**

It's perfectly normal to make return trips to the hospital after the transplant, even to stay for a few days, especially during the first three months. I've come to think of these as "aftershocks" after an earthquake; they're still serious, but you've already survived the big one. Just understand that it's a normal part of the process, and doesn't mean the world is falling apart.

### **You may have to suffer some indignities.**

This may be a bigger deal for younger patients, but you usually undergo things like urological exams, which are often somewhat invasive. I had to home-administer an IV infusion through a PICC line (an IV line that stays in place) for several weeks to treat an infection. But after my transplant and recovery, my response has always been, "I've seen worse." You will have, too. Just try to take it in stride.

### **You do have to be vigilant about your health.**

I've written earlier articles about living with a transplant, so I'll just summarize the main points: stay away from germs wherever they may be, take your medications religiously, partner with your transplant team to monitor your health, and enjoy the exercise opportunities your renewed health affords.

### **Don't be afraid of becoming an activist.**

You may find that you have a different perspective on things after your transplant. You'll likely be thankful for the "ordinary" things you're now able to do. You'll fully understand how life-restoring a transplant can be, and you may be impatient if not indignant with folks who unthinkingly squander their health. Don't be afraid to speak up, step out, and promote the cause. Life and health are too valuable to waste. You now know what many others don't.



## SO YOU THINK YOU MIGHT DONATE A KIDNEY?

*By Douglas Babcock, Kidney Donor*

\*\*If you have a friend or family member who is considering donating a kidney, you may want share the following information, from a kidney donor's perspective:

### **So you think you might donate a kidney?**

It's a serious question. Until now, you may not have given it much thought. But if you want to drastically change someone's life – including your own – give it some consideration. My decision to donate a kidney was easy.

I gave one to my son, Kris. It was the most incredible experience of my life. Let me share some of my insights with you.

### **You will watch an amazing transformation!**

As I stated earlier, I gave a kidney to my son. But regardless of who receives your donated kidney, their transformation from sickness to health will amaze you! My son received his transplant just a few short months ago, and already he's like another person. His eyes are bright. His skin is fresh. His whole attitude and demeanor have drastically changed. There is not a single doubt in my mind that people receiving a kidney from a living donor start feeling much better quickly.

### **The testing is simple and painless.**

Before I could be considered a candidate as a living kidney donor, I needed to pass several tests designed to ensure two things. First, the surgical team wanted to make sure that I would be donating a healthy kidney. This was certainly my main concern. I wanted my son to have the very best shot of getting healthy that he could have. However, while the surgical team was indeed concerned about that as well, they were also concerned about my health.

The second purpose of the testing was to ensure that I would remain healthy AFTER I donated a kidney. This is something that I did not consider, at least not too seriously. My doctors talked with me a lot about staying healthy after the donation. Exercise and eating a healthy diet were really important for staying healthy after my donation. In my case, the primary concern of my doctors was that I keep my blood pressure in the low-normal range. High blood pressure has adverse affects on the kidneys.

### **Your life will quickly return to normal.**

My surgery was laparoscopic, so it was much less invasive than "traditional" surgery. In fact, I was released from the hospital the following day! I had virtually no pain associated with the surgery and was able to return to work – although at a much slower pace – within two weeks. I was also able to return to my normal exercise routine within three weeks!

One of the most noticeable side effects of the surgery for me was that the anesthesia remained in my body for several weeks after the donation. I am an avid cyclist and I noticed that my breathing did not return to normal for almost eight weeks.

### **The donated kidney is removed from the FRONT!**

This piece of information amazes most people, but my donated kidney was removed from the FRONT of my body. I now have a small vertical scar around my belly button as well as a few smaller incisions where the surgeon used various tools during the laparoscopic surgery to free the kidney for removal. These scars will continue to fade away with time.

### **You will have a change in attitude.**

I do not know the exact statistics, but I know that there are more people waiting for kidneys than there are kidney donors. Many people – young and old – are undergoing dialysis even as you read these words. I gave these people very little thought prior to my experience this year, but they are on my mind a lot now.

One of the best things people can do to help is to become an organ donor. The next time you renew your driver's license, tell the good folks at the DVM you want to be an organ donor. They will put a small heart on your license next to the expiration date indicating that you are an organ donor. This very simple loving act may someday give someone a new lease on life.

## So You Want To Donate...Continued

### A final story

I remember pulling my bicycle from the trunk of my car one year as I prepared for the Raven Rock Ramble, a local bicycle ride that benefits the NC Kidney Foundation and the Transplant Games. Parked next to me was a young man who was also preparing to roll out to the starting line. His girlfriend was pinning a picture on the back of his jersey and I asked him about it. He told me that it was a friend of his who was waiting for a double lung transplant. He went on to tell me that he had received a double lung transplant himself earlier that same year! I was dumfounded. The Raven Rock Ramble is a very challenging ride. I was amazed that he was participating.

But this is not an unusual story in the community of organ recipients. The strength and renewed purpose that these people show after receiving an organ donation is simply amazing.

Well, I saw that young man with the picture on his back riding in front of me as the Raven Rock Ramble rolled out from Harris Lake Country Park that year. I was so impressed with him. I started to ride up beside him to ask his name, but I never reached him. He was just too fast!

For more information on organ donation, check out [www.shareyourlife.org](http://www.shareyourlife.org) or [www.organdonor.gov](http://www.organdonor.gov).

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### *Why so Many Questions Continued...*

Why are you asking about things that seem completely unrelated to my kidneys – such as if I was born prematurely or about my dental work?

We try to collect information on a variety of things that MIGHT be associated with some type of kidney disease. Many of the things we ask about have probably not been previously linked to your specific kidney disease, but we need to ask everyone so we can compare different things between different diseases. We read through many studies that have already been published and also talk to patients and their families. However, we realize that the purpose of each question might not be completely obvious. For example, there is some information that being born earlier than normal or having periodontal (gum) disease may put someone at risk for kidney problems later in life, but it has not been reported to be associated with any specific kidney or glomerular disease.

I have been diagnosed with a kidney disease, but have had few or no problems with my kidneys for many years. Should I still complete the questionnaire?

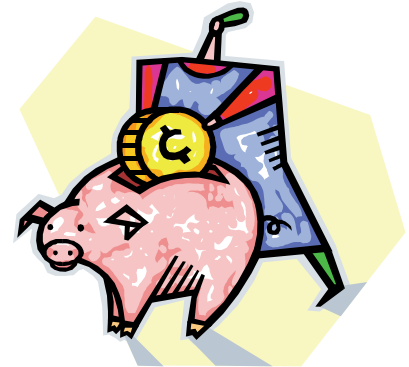
Yes, it is very important that everyone who is sent a questionnaire complete it. People who have had a difficult time with their kidney disease may be more likely to complete study questionnaires because they are motivated to learn more about the disease that has had such a strong influence on their life. However, we can actually learn more about what has made this happen if those with fewer problems from the disease also participate.

## KIDNEY TRANSPLANTATION: UNDERSTANDING THE COST AND THE NEED FOR A PLAN

By Clara Neyhart, BSN, CNN and Lynn McCoy, RN, CNN

Kidney transplantation can offer a whole new life for patients with kidney disease. However, that new life comes with the reality of medications, lab work, possible readmission to the hospital, and clinic visits necessary to maintain the kidney. It is extremely important to understand the costs associated with kidney transplantation, and to have a financial plan to cover them. Kidney transplant is not a cure, but it can be a very successful treatment if you plan ahead for it.

As patients focus on receiving a kidney transplant and ending a life of dialysis, there is a natural tendency to avoid the unpleasant subject of finances. However, whether one has Medicare, Medicaid, or private insurance, there are huge differences in coverage for medications, as well as outpatient and inpatient care. Limitations may exist related to which transplant center provides the transplant surgery, medication coverage, where lab work is done, and where follow up care is provided. In a recent study published in the journal *Transplantation*, over 600 liver and kidney transplant patients were surveyed regarding the financial burden of transplantation. About 40 % of the kidney transplant recipients reported financial problems for themselves or their family after transplantation. Some of this related to unexpected costs and poor planning. (Rodriguez et al, 2007 Aug 15; 84(3), 295-300.) Patients MUST take the time to fully understand their insurance coverage so that a plan can be made for long term care after transplantation. As an example, many patients rushed out to obtain Medicare Part D, which rarely covers immunosuppressive medications. In addition, some patients do not understand that there is a limit to the length of time immunosuppressive medications are covered by Medicare part B. If you are under 65 and do not have Medicare due to disability, your Medicare coverage will end 36 months (3 years) after transplantation. Some insurance plans offer no coverage for costs related to transplantation, or there may be a cap on coverage for these costs. The key is to understand the costs and make your plan BEFORE the transplant.



Please do not let this information discourage you from seeking a transplant, but simply use the information to your advantage. Here are a few tips:

- ⇒ Before referral to any transplant center, find out whether your insurance company has “preferred transplant centers” where care is covered. Most transplant centers have financial counselors who will double check this information before you proceed with an evaluation.
- ⇒ Understand that costs of transplantation include the evaluation, the transplant surgery and hospital stay, medications, frequent lab work, outpatient clinic visits, readmissions to the hospital, and the cost of any complications. Also consider lost work time for both hospitalization and outpatient care following transplantation. Try to plan for all of these costs.
- ⇒ If there is a living donor involved, understand your insurance coverage for that donor’s evaluation and hospitalization. Donor costs are usually covered by the recipient’s insurance, but there are great variations in how much is covered. You do not want your donor saddled with financial loss because the insurance coverage was misunderstood. There may be more than one donor evaluated, and although only one will donate a kidney, and they will all be charged for the evaluation. Remember that the donor will lose work time and could suffer complications as well. Again, the financial counselors should be able to help you sort through this.
- ⇒ Consider fund raising before transplantation, even if you think you won’t need it. The National Transplant Assistance fund ([www.transplantfund.org](http://www.transplantfund.org)) can help you create a fundraising campaign to pay for medical expenses.
- ⇒ Transplantation is a wonderful option for treatment of kidney disease. Just remember, the cost may be considerable and different for everyone. Some transplant centers have pharmacy benefit programs and other resources to help you. Please think ahead and develop a plan with your transplant health care team!



The Focal Segmental Glomerulosclerosis (FSGS) 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 have 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](mailto:leslie_powell@med.unc.edu). You can also check out the national website: [www.fsgstrial.org](http://www.fsgstrial.org).



This study is being conducted to learn more about how chronic kidney disease (CKD) effects children. CKD happens when the kidneys have trouble removing waste products from the blood. The number of people with CKD continues to grow, and it is anticipated that 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, and children still have years of growing and development ahead of them. 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 < 70, at 57 medical centers, including UNC Hospitals. For more information, please call Sandy Grubbs, RN, CPNP at 1-866-462-9371, or by e-mail: [sgrubbs@med.unc.edu](mailto:sgrubbs@med.unc.edu).

### Sleep Disturbances in Children with Chronic Kidney Disease

Very little research has been done looking at the relationship between chronic kidney disease (CKD) and sleep disturbances in children with CKD. Many studies in the adult CKD population have shown higher levels of sleep disorders, raising concern that similar results will be found in the pediatric CKD population.



To try to better understand sleep disturbances in children with CKD, this study includes a series of questionnaires that ask about several aspects of the participants' sleep habits, a quality of life questionnaire, and a week-long sleep diary, where participants note what time they go to bed and wake up each day.

It takes about 30 minutes for participants and their parents to fill out the questionnaires, and many participants finish the questionnaires while waiting to see the doctor. The study includes all CKD patients between ages 5-18, GFR  $\leq$  75, with no mental delays. For more information, please email Amy Kuchenreuther at [Amy\\_Kuchenreuther@med.unc.edu](mailto:Amy_Kuchenreuther@med.unc.edu).



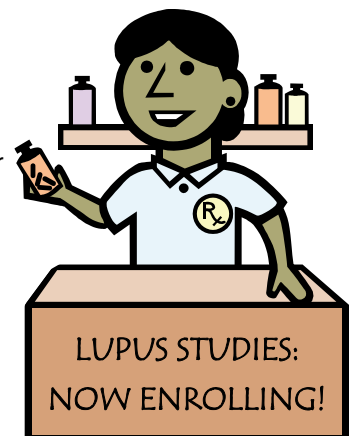
## LUPUS STUDIES UPDATE

There are 3 treatment trials for lupus currently enrolling patients at UNC. These studies include patients with stable or mildly active lupus, patients who have new or recurrent kidney inflammation (lupus nephritis), and those with 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.** For all lupus clinical trials, there is no charge for the visit, study drug, laboratory studies, EKG and a stipend is provided for travel, meal expense and time donated.

If your lupus has been relatively stable with only mild activity in the past year, you may be eligible to participate in a phase I trial of a new drug to treat lupus. In a phase I study, all participants receive the drug, though different doses are tested. Frequent visits are required to check how the drug metabolizes and make sure that it is safe and well tolerated. The study visits occur during a 12 week time period, working around your schedule as much as possible. If the drug shows promise, future studies will examine whether the drug is effective in treating lupus. Usually one or just a few doses are given in the study. There is payment for travel, meal and parking expenses for all study visits. Brenda Meier, RN can provide more information about the study at the contact numbers above.

If you have lupus nephritis that is recently diagnosed or has become active again (kidney biopsy within 3 months), 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 (cellcept). 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 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.

If you have severe symptoms of lupus without lupus nephritis, then you may be eligible for another study of anti-BLYS compared with placebo. 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, RN, Lupus Clinical Trials 919-843-6619 or beeper 919-216-1185** to learn more about this study.



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. The study requires only 1 visit a year. No medications are tested so your lupus therapy will not be changed. 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.



For more kidney disease information,  
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this newsletter, check out our website:

[www.unckidneycenter.org](http://www.unckidneycenter.org)

## NOW ENROLLING: CLINICAL TRIAL FOR POLYCYSTIC KIDNEY DISEASE PATIENTS

If you have **Autosomal Dominant Polycystic Kidney Disease (ADPKD)**, you may be eligible to enroll in a Phase 3 clinical trial to determine the efficacy of a medicine called Tolvaptan .

With ADPKD, the kidneys respond abnormally to a hormone called vasopressin, which may be involved in cyst development or cyst growth. Tolvaptan interferes with vasopressin's effects on the kidney and, when taken continually, appears to stop cyst growth in laboratory animals with ADPKD. It is hoped that similar effects will be seen in humans.

### You may be eligible for this study if:

- You are between 18-50 years old;
- Your Glomerular Filtration Rate (GFR) is  $\geq 60$  mL/min/1.73m<sup>2</sup>;
- You have :
  - several cysts in each kidney (3 if by sonography, 5 if by computed tomography (CT) or MRI) **and** a family history of ADPKD or;
  - 10 cysts in each kidney (by any radiologic method)
- Your kidneys have a total size  $\geq 750$ cc (This will be checked by a MRI before starting the study).

### You should not be participating in the study if:

- You are not able to take an MRI (severe claustrophobia, ferromagnetic metal prostheses, aneurysm clips, large abdominal/back tattoos);
- You have other kidney diseases, a single kidney, recent kidney surgery;
- You are regularly taking diuretics ("water pills") to control hypertension;
- You are on dialysis.

If interested, or if you have more questions, please contact Anne Froment at 919-923 1382, or at [anne.froment@med.unc.edu](mailto:anne.froment@med.unc.edu). You can also leave a message on our toll-free patient line: 1-866-462-9371

## ACTION ALERT! HR3282: COMPREHENSIVE IMMUNOSUPPRESSANT DRUG COVERAGE FOR KIDNEY TRANSPLANT PATIENTS ACT OF 2007

Did you know:

- If someone only has Medicare due to end-stage kidney disease (ESKD), and not due to age >65 or disability, their Medicare coverage ends 36 months after transplantation?
- Transplant medications can cost between \$10,000 and \$20,000 per year?
- Without immunosuppressant medication (also known as anti-rejection drugs), a transplanted kidney will stop working?
- People who can't afford their immunosuppressives and stop taking them will most likely lose their transplanted kidney and have to go back on dialysis?



House Bill 3282, introduced this session in Congress, would make it possible for ESKD patients under 65 who are not classified as disabled to keep their Medicare Part B benefits throughout the life of the transplant. Under this legislation, a kidney transplant recipient would have access to these drugs under Medicare Part B by paying the premium. Medicare would be the secondary payer if the patient has private insurance.

Please urge your Congressional Representatives to support this bill and extend immunosuppressant coverage beyond 36 months to ALL transplant recipients. Go to this webpage: <http://capwiz.com/kidney/issues> and click on "Legislative Issues and Update". From here you access sample letters and can contact your representatives to let them know you support this important issue for kidney patients.

If you live in North Carolina and want to set up a meeting with your legislator, please contact Caroline Jennette at 919-966-2561 ext.301, toll-free at 1-866-462-9371 or by e-mail at [caroline\\_jennette@med.unc.edu](mailto:caroline_jennette@med.unc.edu).

Thanks for adding your voice to the political process!!

## RECIPE BOX: PUMPKIN BREAD

Diet type:  CKD non-dialysis  Dialysis  Diabetes



**Portions:** 3 loaves with 10 slices per loaf  
**Serving size:** 1 slice

### Ingredients

- 2 cups sugar
- 2 cups canned pumpkin
- 2/3 cups water
- 4 large eggs
- 1/2 cup cooking oil
- 1/2 teaspoon baking powder
- 1 teaspoon cinnamon
- 1 teaspoon ginger
- 1 teaspoon salt
- 2 teaspoons baking soda
- 3-1/2 cups all-purpose white flour

### Preparation

1. Preheat oven to 350° F.
2. In a large mixing bowl beat together sugar, pumpkin, water, eggs and oil.
3. Add baking powder, cinnamon, ginger, salt, baking soda and flour. Stir until smooth.
4. Pour batter into 3 loaf pans and bake for 45 minutes or until inserted toothpick comes out clean.

### Renal and Renal Diabetic Food Choices

1 starch  
 1 fat  
 1/2 high calorie

### Carbohydrate Choices

1-1/2

### Helpful Hints

To modify for a low-fat, low-cholesterol diabetic diet, substitute 1/2-cup low-cholesterol egg product for two of the eggs and substitute 1-cup Splenda® granular sweetener for 1-cup sugar. Carbohydrate is reduced to 18 grams, fat to 4 grams, cholesterol to 14 mg and calories to 120.

### Nutrients per serving

- Calories: 145
- Protein: 3 g
- Carbohydrate: 24 g
- Fat: 5 g
- Cholesterol: 28 mg
- Sodium: 171 mg
- Potassium: 61 mg
- Phosphorus: 38 mg
- Calcium: 15 mg
- Fiber: 0.8 g

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

Recipes Provided Courtesy of Davita Dialysis  
 Please visit [www.DaVita.com/recipes](http://www.DaVita.com/recipes) to find more recipes.

## RESOURCE CORNER: ONLINE SUPPORT GROUPS

### National Kidney Foundation Message Boards:

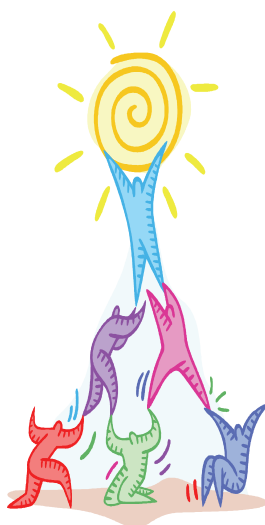
Includes Message Boards for : Donor Families, Transplant Recipients, Living Donors, and Kidney patients and their families.

<http://www.kidney.org/patients/mboards.cfm>

### The Renal Support Network's Kidney Space:

Provides a forum for kidney patients to talk about a variety of subjects, including lifestyles, dialysis, general discussion, advocacy, and a teens only section:

<http://www.kidneyspace.com/>



### The NephCure Foundation's NephSpace Community:

This is an online community for families and caregivers dealing with Nephrotic Syndrome and Focal Segmental Glomerulosclerosis (FSGS).

<http://nephcure.org/NephSpace.html>

### Home Dialysis Central Forum

An online community for patients on Peritoneal Dialysis or Home Hemodialysis to share their experiences and learn from each other.

<http://forums.homedialysis.org/>

A Newsletter from the  
Glomerular Disease  
Collaborative Network

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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](http://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](http://www.unckidneycenter.org) (1-866-256-2930) or  
[www.nkdep.nih.gov](http://www.nkdep.nih.gov) (1-866-454-3639)