

KIDNEY CARE



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

Co-Directors:

Ronald J. Falk, MD, and
J. Charles Jennette, MD

Research Director:

Susan L. Hogan, PhD

Pediatric Research Director:

Debbie Gipson, MD

Study Coordinators:

Kristi Bickford
Jill Cooper
Ted Ferris
Caroline E. Jennette, MSW
Brenda Meier, RN
Michelle Mitchell
Leslie Powell, RN, CPNP
Amber Thompson, RN

Statistician:

Hyunsook Chin, MPH

EMERGENCY PREPAREDNESS FOR KIDNEY TRANSPLANT PATIENTS

By David Cole

On Thursday evening, October 5, a fire started at a chemical storage company in my home town of Apex, NC. Very early the next morning, 17,000 people were told to evacuate immediately. Many people thought they'd be back in a few hours and left their pets, clothes, and even medications behind. But, it wasn't until two days later that the OK was given to return. Most folks can manage a day or two of unexpected circumstances, such as during a hurricane or ice storm, but if you have a kidney transplant like me, then you have an extra set of concerns.

Perhaps the most immediate concern is maintaining an adequate supply of medications. Our anti-rejection drugs keep us alive, and it's important to have provisions for unexpected, but possible, circumstances. For example, what if you were traveling and your luggage (containing your medications) was lost? What if, like on September 11, you were delayed at a location several days longer than you expected? Even if you have your medications with you, what extra precautions do you need to take when traveling?

Here are some simple suggestions to handle these types of situations:

1. Use a large, week-long pill box. Not only does this help you remember whether you've taken your meds, but it gives you a convenient container to grab when you are leaving unexpectedly, or pack when you're traveling. You can find a plastic pill box at most drug stores, and they are inexpensive.
2. Keep an extra week's supply of your meds, and pack separately. I keep an extra supply of my anti-rejection drugs in my shaving kit, and pack this in a separate bag from my usual medications. This gives me an extra supply of medicines, and makes sure I have some medicine if a bag is lost by the airlines. I replace these medicines about every three months, to keep them fresh.
3. Carry your medications on board with you when traveling.
4. Carry at least one set of meds with you, so you'll have them regardless of what else happens.
5. Carry a list of your medications with you. I'll talk more about this later, but if you had to call a transplant center to request emergency drugs, you need to know exactly what you're taking, and at what dosage.

Continued next page →



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

www.unckidneycenter.org

or call toll-free 1-866-462-9371

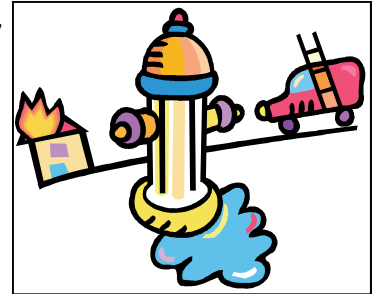
“Living successfully with a transplant requires that you be very aware of your own health, and better at protecting it than you might be otherwise.”

(cover story cont.)

Of course, there’s more to be concerned about than just your medications. It’s also important that you keep yourself germ-free, and traveling presents special problems because you are close to so many people. Here are some more common-sense suggestions:

1. Travel with a face mask, and use it if anyone near you is obviously sick. You can get these at your transplant center or at a drug store.
2. Wash your hands a lot (even more than you might already) when traveling, and avoid touching surfaces. Carrying hand sanitizer is a good idea, too.
3. Avoid travel and busy places during flu season. I myself have sometimes decided not to go on business trips during flu season, and my employer was very understanding.
4. Carry antibiotic wipes to use on phones and surfaces. People may think you are a “germ-phobic”, but it’s just taking reasonable precautions to keep yourself healthy!

There’s one other situation you should plan for, and that’s being taken to a hospital for any reason. In some situations, you may be unconscious and unable to explain your medical history, medications, etc. Transplant patients have special needs and are treated differently from other patients, and if you have to go to a hospital you should try to find one with a transplant center. Something I’ve discovered from my own experience is that doctors always seem to ask the same questions, so I’ve prepared a set of papers that answer those questions. My list s include:



1. A complete list of medications, dosage, and why they are taken, including current and prior medications. It’s good to know, for example, if you have previously tolerated a medication well, or if you had to stop a previous medication because of bad side effects.
2. A list of past hospitalizations, procedures, and test results. If you think about it, you’re asked for this information any time you see a new doctor, and having the information ready can save a lot of time.
3. A list of doctors and all contact information, along with contact information for friends, family, and coworkers. This can be really important if you are out of town and the doctor needs to talk with your kidney doctor, transplant nurse, or another member of your health care team.
4. Personal information, including social security number, date of birth, emergency contacts, and insurance information. It’s important to guard this information, but even more important to have it available for medical personnel when needed.
5. Charts showing my creatinine numbers. These are important so doctors will know what’s “normal” for me, and can assess whether I’m undergoing a rejection episode.

With these papers, you have a package that could be handed to an emergency room doctor and he or she would have everything they need to know to understand your background. You can ask your transplant nurse, social worker, or doctor for help creating these information lists.

Living successfully with a transplant requires that you be very aware and knowledgeable of your own health, and be better at protecting it than you might be otherwise, especially in emergency situations.

David Cole

David Cole is kidney transplant recipient, an avid cyclist and kayaker, and a Senior Software Engineer at IBM. He lives in Apex, NC with his wife and two children and receives his care from Dr. Ronald Falk and Clara Neyhart at the UNC Kidney Center. He can be reached by e-mail at:

dcollection@nc.rr.com

FROM PATIENT TO PROFESSIONAL

By M. Ted Ferris

It's a familiar feeling, walking through those glass double doors and across the lined linoleum floor toward clinic. My feet follow the worn path, having walked it many times before. My hands shaking slightly from the cyclosporine, I button my coat as I approach the check-in desk.

Without thinking, I reach for my hospital card. I smile at my reflex, because today I don't need it. Today I won't have to face the dreaded sign-in sheet, the one with the "Time In" column telling how I'm always late to my appointments. I won't have to bust out an insurance card or verify my address and birthday, no sir. Because that coat I was buttoning? It's white. And monogrammed. And boy does it get me past the front desk faster than you can say "study coordinator."

Walking down the clinic hallway, even after being a kidney patient for 20+ years, becomes an all new feeling when you're on the other side of the exam table. Getting to sit in a chair with wheels rather than the barely-cushioned four-legged kind makes more difference than you can imagine. Simply not having to wait in the room-most-aptly-named for half an hour is like a night and day experience.

After receiving a transplant nine years ago, and getting the chance to follow my dream of working in Hollywood for the last two, I had a very serious episode of rejection. It forced me to come back home, nurse my wounds, and much to my surprise – find there was more fulfilling work than the glamour of movies.

As a study coordinator for clinical trials aimed at conquering some tough kidney diseases, it's been an interesting two months. From going over medicine lists with patients and comparing war stories on side effects, to sadly watching the same stumbling blocks befall some of my favorite people.

The most interesting thing I've found is the change in patient demeanor when they find out that I have Chronic Kidney Disease as well. Yes, I've been where you are and I know exactly how you feel. I take that medicine too, and my goodness does the waiting room seem interminable sometimes. It's like a window opening, and their eyes light up because finally – finally! – someone who understands is on the other side of the stethoscope.

Not that doctors or nurses don't care for their patients as if they were family members – they do – but because no one but those who suffer from kidney disease know the real hardships that face us. And if for no other reason than moral support, I go into work every day hoping to help – with an ear, a shoulder, or a very understanding smile.

The greatest part of my job? I get a little thrill every time I walk out of clinic because despite my initial reflex, I don't have to leave behind a white topped tube of yellow liquid to be studied by the lab.

This article was reprinted, with permission, from the American Kidney Fund's Professional Advocate Newsletter.



KidneyTalk!TM
Streaming
Health, Happiness & Hope
over the Internet



KidneyTalk! is an online radio show blending humor, insight, and useful information on living life to its fullest in spite of kidney disease

A new half-hour show is uploaded to RSNhope.org every Tuesday.
Each new show is available online 24/7 for an entire week.
All shows archived at RSNhope.org and are available as a podcast.

Listen to **KidneyTalk!** online at:
RSNhope.org

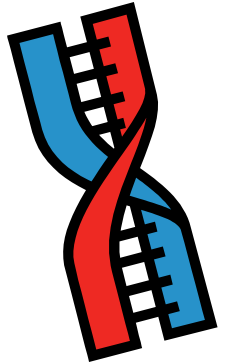


With your hosts
Lori Hartwell
and
Stephen Furst

Order a CD of
past broadcasts
at RSNhope.org!

NOW ENROLLING: POLYCYSTIC AND GENETIC KIDNEY DISEASE REGISTRY

If you have Polycystic Kidney Disease or another genetic kidney disease (e.g. Medullary cystic disease, Alport's/thin basement membrane) you can now enroll in our genetic kidney disease registry by contacting Jill Cooper (contact information below). We are collecting information on kidney disease patients with known or potential genetic components. Informed consent is all that is required at this time to enter the registry. This registry will also serve as a venue for enrollment into clinical trials in the future.



If interested, or if you have more questions, please contact Jill Cooper at 919-966-2561 x284, toll-free at 1-866-259-2230 or at jill_cooper@med.unc.edu

LUPUS STUDIES UPDATE

There are 2 treatment trials for lupus currently enrolling patients 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 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), either 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 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 **severe symptoms of lupus without lupus nephritis**, then you may be eligible for another study of **rituximab 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, Lupus Clinical Trials 919-843-6619 or beeper 919-216-1185 to learn more about this study.

There may be new treatment trials starting up in early 2007. Please feel free to call for additional information.

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 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.



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 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.



The FSGS Novel Therapies (FONT) Study began enrolling patients in 2006. The study is funded by the National Institutes of Health Division of NIDDK. The purpose of the first phase of this study is to investigate the tolerability, safety and optimal dosing of two new drug therapies for FSGS for patients who have failed to respond to conventional therapies. In this first phase of the study, 20 patients will be enrolled to evaluate new therapies for treatment, focusing on renal protection and antifibrosis in the kidney as opposed to an immunologic target with conventional therapy. Once safety, tolerability and dosing are established, the next phase of a larger study will be to evaluate the efficacy of the two agents.

The study will enroll 20 patients, ages 2-40 with a GFR \geq 40ml/min/1.73² who are non-responsive to steroids and immunosuppressive therapy such as cyclosporine, mycophenolate mofetil (MMF), sirolimus, tacrolimus, and imuran. For more information please call Amber Thompson at 1-866-462-9371, or by e-mail: amber_thompson@med.unc.edu. You can also check out the website: http://www.med.unc.edu/medicine/uncrenal/fsgs/FONT_000.htm

RECIPE BOX:

CHICKEN VEGETABLE LINGUINE

Diet type: CKD non-dialysis Dialysis Diabetes



Servings: 2

Serving Size: 1 Cup

Ingredients:

- 1 pound of boneless, skinless chicken breasts
- 3 tablespoons extra virgin olive oil
- 1/2 package (8 ounces) linguine
- 3/4 cup broccoli
- 3/4 cup cauliflower
- 3/4 cup baby carrots
- 16 grape tomatoes
- 2 tablespoons lemon juice
- 3/4 teaspoon Mrs. Dash®

Preparation:

1. Cut up chicken into small strips.
2. Heat pan on medium heat with 2 tablespoons extra virgin olive oil.
3. Add chicken to pan and cook until done.
4. Cook 1/2 package of linguine according to package directions
5. Cut up broccoli and cauliflower to bite-sized pieces
6. When chicken is cooked, add broccoli, cauliflower, carrots, tomatoes and lemon juice, cover and cook for 3 minutes.
7. Add drained pasta to pan and then add 1 tablespoon extra virgin olive oil and stir.
8. Add Mrs. Dash®, stir and simmer on low for 5 minutes.

Nutrients per serving:

Calories 343
 Protein 25 g
 Carbohydrate 38 g
 Fat 10 g
 Cholesterol 61 mg
 Sodium 74 mg
 Potassium 416 mg
 Phosphorus 236 mg
 Calcium 39 mg
 Fiber 1.9 g

Kidney and Kidney Diabetic Food

Choices
 3 meat
 2 starch
 1 vegetable, medium potassium

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 to find more recipes.



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 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 < 70, at 57 medical centers, including UNC Hospitals. For more information, please call Amber Thompson at 1-866-462-9371, or by e-mail:

amber_thompson@med.unc.edu.



UPDATE: The Board of The Kidney Coaching Foundation, Inc has been hard at work! There have been programs developed, fundraisers planned, and connections made...all in anticipation of the great opening.....but wait, there is one thing missing.....YOU! Yes, you! There is space available for your time, skills and effort. If you'd like to be a coach, we want to hear from you. Who are we looking for?

- Must be between the ages of 16-35
- Must be compliant with all doctors orders
- Must have dealt (either personally or as a caregiver) with a chronic illness
- Must have a positive attitude and be an inspiration for having health success
- Must be willing to share their experiences
- Must have a good recommendation from their current doctor and 2 professional references
- Must go through a criminal background check

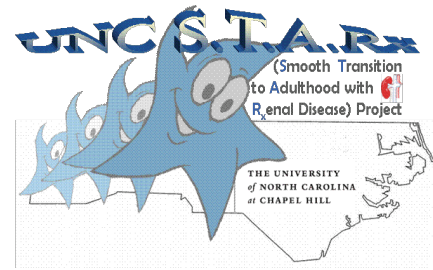
We are also looking for those who would like to volunteer in other ways and/or give to our cause – our cause...what is it? GLAD YOU ASKED!

Through group and one-on-one coaching programs our goal is to provide each member of our program with a trained volunteer coach who guides them in acquiring the tools necessary to comply with their medical treatment. We will also assist the patients in creating and achieving goals that will foster a proactive, responsible stance about their medical care, as well as acquire a positive conviction about their ability to plan and make choices that have an affirmative impact on their future. – WHEW! A mouthful, but a powerful and important tool in improving the lives of our future generation!

So, if you fall in any of the categories of needs above, we'd love to hear from you and make you a part of the KCF family! For more

Until next time,
Deidra Hall, Board Chair. KCF

TRANSITION TO ADULTHOOD WITH KIDNEY DISEASE:
BUILDING A SUCCESS STORY



María E. Díaz-González de Ferris, MD, MPH, PhD

Due to technological and medical advances, many children who are diagnosed with kidney disease now survive to adulthood. Bridging the gap between their pediatric and adult medical homes has become an important aspect to their psychological and social transition from youth/adolescence to adulthood. Transition is a process that culminates with the transfer from pediatric to adult health care providers. It is designed to enhance the self-management of young adults with complex medical conditions. This process takes time and the efforts of many team members: The patient, his or her parent(s), siblings, pediatric and adult health providers, school teachers, community local organizations, and national organizations.

The family that is blessed with having a child with a chronic illness has to deal with many difficult challenges. Time spent in the health care facilities is time away from home and school, impacting the child's ability to develop a social network and the parents' employment. The healthy siblings may feel cheated of their parents' time. With these complications, how do we help these adolescents transition successfully?

One of the reasons why the transition process is so important to me, other than the fact that I am a pediatric nephrologist, is because I have experienced the transition process first-hand. My oldest son was diagnosed as having chronic kidney disease when he was a baby and underwent over 30 surgeries (major and minor). When he was 15 years of age, he received one of my kidneys (which did not work) and a year later received one of his father's kidneys. Even after a life threatening complication which may have led him to lose his kidney, it is still working. This experience, in many ways, led me to my field of research: Transition.

In the pediatric nephrology field, Transition work is at its early stages and our program at the University of North Carolina Kidney Center (UNCKC) is developing both a Transition program and the tools to measure it through our "Successful Transition to Adulthood with Renal Disease" (STARx) program. We hope to eventually make this program available to all nephrology practices, so that their young patients can benefit from what we are learning.

There are many questions that need to be answered: How do we empower young patients to manage their disease effectively and efficiently? How do we help the parents to learn to "let go"? How do we improve communication between pediatric and adult nephrology team members? How can busy programs with limited resources have a successful Transition program? Can this Transition program be adapted for patients and families with different cultures and educational backgrounds?

We have started by asking focus groups of parents, as well as transitioning/transitioned patients how to best approach the Transition process. We are giving medical passports to our patients, so that they can better understand and keep track of their medical information. We have also developed a Transition Score to track progress and are currently developing tools to assist parents with their own questions about Transition.

As you can see, there is much to be done in this field! No doubt the love of Mike, my husband of 28 years, the patience of my children, and the care of my patients all have contributed to developing this rewarding work.

For more information on children and kidney disease, or to get your child involved in the STARx program, please contact Kristi Bickford, Transition Coordinator, at 919-966-2562 ext. 246, toll-free at 1-866-462-9371, or by e-mail: kristi_bickford@med.unc.edu.

Dr. Maria Ferris is the mother of three children, and is a pediatric nephrologist and Associate Professor at the UNC Kidney Center in Chapel Hill, NC. She is the principal investigator of the STARx program.

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

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



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