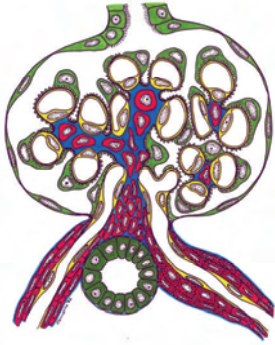


KIDNEY CARE

This Newsletter was approved by
the Committee on the Protection of
the Rights of Human Subjects
University of North Carolina
7/18/05



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 Hogan, PhD

Pediatric Research Director:

Debbie Gipson, MD

Study Coordinators:

Jill Cooper
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Research Assistants:

Sheri Kremer
Michelle Mitchell

LIFE AFTER TRANSPLANT: ONE PATIENT'S STORY

"Hmmm – this doesn't look good."

Not the kind of words you want to hear from your doctor when you go in for a checkup. He had just noticed protein and red blood cells in my urine sample, and knew something was amiss. Fast forward a couple months and a kidney biopsy later, and a kidney specialist is telling me that I have IgA Nephropathy and can anticipate the need for a kidney transplant in five years or so.

This seemed unreal. I was an active, long-distance cyclist and had just set a new personal record for 100 miles a couple months before. I had noticed, though, that my blood pressure had been rising slowly, and I certainly had noticed the leg cramps that were occurring with increasing frequency as I cycled. What followed over the next 2-1/2 years was a gradual decline in kidney function, at which point I was told to start searching for a donor and making plans for a transplant within the year.

Now I was in uncharted territory – so many things to learn and understand. I didn't know that I would have to qualify as a recipient, and that donors would have to go through an even more demanding evaluation. I had no idea what life would be like after the transplant, or if I'd ever be able to bike again. Naturally, my wife was even more concerned; she was wondering if I'd even survive, and how she'd be able to manage the family if I were gone.

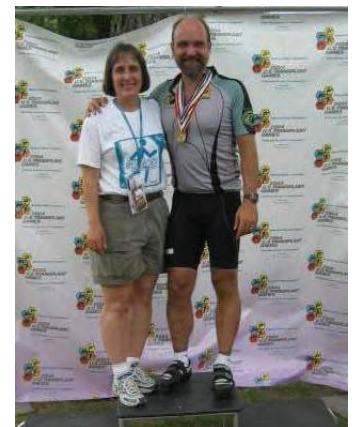
All these fears were natural. One consolation I kept reminding myself of was that Sean Elliot, an NBA basketball player at the time, was back playing in the NBA after receiving a kidney transplant. If he could have that strong a recovery, perhaps I could, too.

End stage renal disease is no fun. I was becoming more anemic and uremic, and was tired and sick more often than not. Just climbing a flight of stairs left me with a racing heartbeat, and my blood pressure was so high it scared me. One of the things I learned at this stage is that you find a way to cope with whatever you have to, and I was coping best I could.

With the help of my doctor at UNC, we were able to schedule the transplant just before I would have needed dialysis. My sister Laura was my donor. We both had several things going for us. We were in otherwise good health, not overweight, and not smokers. Here's something I didn't know until shortly before the transplant (shows how naïve I was): with a kidney transplant, nothing is removed - the new kidney is simply "plumbed" in. Thus, the surgery is somewhat more involved for the donor than for the recipient.

Laura was admittedly sore for a few weeks. I was too, but within just a few days I was feeling much better than before the transplant. I was transitioning from being very sick to becoming well again.

Continued next page →



David Cole with his sister and donor Laura Long
at the 2004 US Transplant Games

*“Learn what you can,
cope with what you have
to, take ownership of
your health, and be
hopeful of good things to
follow”*

(cover story cont.)

Even so, I discovered that it is very common to return to the hospital within the first three months after a transplant, and I returned twice, once with an infection and once again with a rejection episode. What made these issues no more worse than they were was that I was following my nephrologist’s advice very carefully. I was especially diligent with my new medication regimen, which started out at 39 pills a day (and has since stabilized to a mere 17 a day).

As the days and weeks passed, I was once again able to start cycling, and experienced a sort of “reverse aging.” That is, I’d go for a ride, and then look in my cycling diaries to see how long it had been since I had gone that fast or that far. A little over a year later I even set a new personal record – something I never, ever expected would happen.

It’s important to know that a transplant is a treatment, not a cure. You trade one set of problems for another, but usually the trade is in your favor. You have to adopt a strong sense of ownership about your own health. For example, being immune suppressed makes you much more susceptible to germs and sickness, so I wash my hands many times each day and will move away from someone in public who’s sneezing or coughing. I also believe you should take on a partnership with your doctor and transplant nurse. They can offer only so much advice – you’re the one who has to follow it, and advise them if there are problems. One problem for sure can be cost. My medications would cost about \$20,000 a year without insurance. Sadly, transplantation may not be an option for someone who doesn’t have the insurance or resources to cover both the surgery and the medications [see page 8 for information on a bill to increase medication coverage for transplant patients].

I was surprised to discover that because I’d be immune suppressed I should not have reptiles, birds, or cats as indoor pets because of certain germs they may carry. I wasn’t surprised (nor disappointed) that I should avoid raw meat and uncooked eggs. Anti-rejection drugs have other side effects, which can vary from patient to patient. I have to be wary of skin cancer, so I wear a hat when I’m outside and use plenty of sunscreen. My drugs also cause insomnia, so I have to manage my sleep and usually take a sleeping pill each night. All these things seem minor, though, when I compare my overall health now with prior to the transplant.

One of the most inspiring things I’ve done was participate in the US Transplant Games in 2002 and 2004. These are Olympic-style events for organ transplant recipients, and everyone there had a story similar to my own. It was uplifting to meet folks who had had their transplants for over 25 years! There were some very good athletes there, including Sean Elliott, and I felt fortunate to come home with medals in the two cycling events. In 2004 my sister joined us at the games, and she was able to watch part of herself win the races!

If I were to face a transplant again, I’d do so with much less fear. Yes, there’s an ordeal to endure, but there’s much improved health and lifestyle on the other side. Should you find yourself confronting end stage renal disease, I’d encourage you to learn what you can, cope with what you have to, take ownership of your health, and be hopeful of good things to follow.

Written by 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: dcole@nc.rr.com



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

www.unckidneycenter.org

MAKE A DIFFERENCE AT YOUR FAMILY REUNION:

Help your family Make the Kidney Connection

If you're planning or attending a family reunion this summer, check out the Kidney Connection Toolkit developed by the National Kidney Disease Education Program (NKDEP). It will help you talk to your family about the connection between diabetes, high blood pressure, and kidney disease at your family reunion.

Why? Because diabetes and high blood pressure are the two leading causes of kidney failure. Many of us know family members who have one or both of these conditions. That's why it is important to talk with family members about what they can do to protect their kidneys.

The number of people in the United States with kidney disease is increasing rapidly, and it strikes African Americans more than other groups. If the kidneys fail, a person must either begin dialysis or get a kidney transplant.

But there's good news. Kidney disease can be treated and kidney failure can be prevented.

You don't have to be a health expert to share this important information with your family. The Kidney Connection Toolkit provides everything you need, including: kidney disease background information, three different ways to incorporate kidney health into the reunion agenda, talking points, and supporting materials.

Depending on what will work best for the family, the toolkit provides simple guides for: 1) conducting a 15-minute Make the Kidney Connection health discussion, 2) identifying family members at risk for kidney disease and having one-on-one discussions with them, and 3) distributing kidney disease prevention information to attendees.

The UNC Kidney Center is working with the NKDEP to spread the word about the Kidney Connection Toolkit. **We encourage** you to visit the NKDEP's family reunion website at www.nkdep.nih.gov/familyreunion for more information and to download the free toolkit, or call Caroline at the UNCKC for printed copies (1/866-462-9371). Also, tell others about the initiative. Each year, hundreds of thousands of families reconnect with their extended family members. With the reality that diabetes and high blood pressure often run in families, the family reunion is a fitting opportunity to make family members with these conditions aware of their risk for kidney disease and to encourage them to get tested.

The National Kidney Disease Education Program is an initiative of the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, U.S. Department of Health and Human Services.

Recipe Box: Dialysis Friendly Morning Muffins*

Reprinted with permission from www.ikidney.com

Serving: 1 muffin, makes 16

Cooking Time: 350 degree oven for 20-25 min.

Key Nutrition Values: Calories: 260
Phosphorus 24 mg
Potassium 65mg
Protein 3g
Sodium 210mg

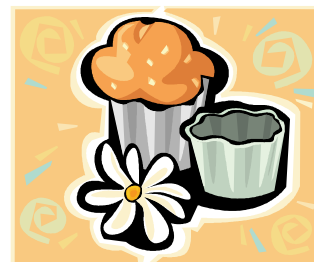
Ingredients:

Margarine	5 Tbsp.
Sugar	1/2 cup
Eggs	1 1/2
Flour	1 1/2 cups
Baking Powder	2 1/4 tsp
Nutmeg	1/4 tsp
Milk	1/2 cup
Vanilla	1 tsp

Instructions:

1. Cream together margarine and sugar.
2. Add egg and mix well.
3. Mix dry ingredients and add to creamed mixture. Alternate with milk and vanilla
4. Grease muffin pans
5. Fill 1/2 with batter and top with mixture of cinnamon and sugar.

1 muffin = 1 starch & 1 fat exchange



*PLEASE CHECK WITH YOUR OWN RENAL DIETICIAN OR HEALTHCARE PROFESSIONAL THAT THE DISH IS SUITABLE FOR YOU.

LUPUS STUDY UPDATE

It's been a busy Spring for the lupus research team with several large projects currently underway. We have just completed recruitment for the AROSE (Revising ACR diagnostic/classification criteria for Systemic Lupus Erythematosus) study, sponsored by the National Institutes of Health (NIH) and the Lupus Foundation of America (LFA). At present, lupus patients are diagnosed on the basis of meeting any four out of a set of eleven various criteria at one time. The ACR (American College of Rheumatology) created these criteria in 1982, with revisions in 1997, but they don't include kidney biopsies or blood tests that are commonly used today.

The purpose of this research study is to determine if these existing criteria still work well, and if not, to make the appropriate revisions. We are expecting approximately 300-350 SLE patients and 350-400 non-SLE controls to participate. For each patient, the physician determines the presence/absence of clinical symptoms, signs, and routine lab tests. It also involves a one-time blood draw. We are conducting this study along with a group of rheumatologists from 25 international centers as a part of "The Systemic Lupus Erythematosus International Collaborating Clinics" (SLICC).

Another lupus project that is underway is the *Carolina Lupus Follow-up Study*, sponsored by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Institute of Environmental Health Sciences (NIEHS). Lupus patients are more likely than others to develop kidney involvement and progression of kidney disease. Some of the exposures we want to examine as "risk factors" for lupus include medical history, work history, exposure to smoking and environmental agents, medications, hobbies, and the presence or absence of certain inherited genes. Information from lupus nephritis patients will be compared to information from people living in the same communities who do not have this disease and to lupus patients without nephritis. We are in the telephone interview phase of this study, which means that subjects are being contacted and asked questions regarding medical history, pregnancies, places they've lived, and family history of certain diseases.

Three Phase I clinical trials will be starting in the fall, and recruitment for the ALMS (Aspreva Lupus Management Study) will commence later this summer. The Aspreva Pharmaceuticals Corporation will be sponsoring the ALMS, which is a treatment trial that will compare the use of IV Cytoxan (Cyclophosphamide) to Cellcept® in the treatment of lupus patients with diffuse proliferative (Class IV) glomerulonephritis. More information about this trial will be available later this summer.

For more information about any of these studies, please contact Marcus Johnson, Lupus Research Coordinator at UNC, at 919-966-2561 ext. 227, or leave a message on the GDCN toll-free patient line (1-800-462-9371).

SAVE THE DATE! SUPPORT GROUP MEETING FOR MEN WITH LUPUS

Systemic lupus erythematosus (SLE) can occur in either sex, and at any age, but lupus is often called a "woman's disease" because it occurs 10-15 times more frequently among females than among males. Keeping this statistic in mind, the lupus study coordinator started speaking with some of our male lupus patients at their clinic visits and was shocked to discover that none of them had ever met another male with lupus. Therefore, we are very excited to announce that we will be hosting our first "Lupus Men's Day" on **August 19th, 2005**. This event was designed with the intent of providing our male lupus patients with the chance to network with each other, and to possibly form a support group in which they could find comfort in knowing that they are not alone, as males, while coping with this disease. The day will begin at 8:30 with breakfast and will feature speakers from a variety of healthcare disciplines that will lecture on health topics that pertain particularly to males, and will end at 12 PM with a lunch for attendees. If you are interested in attending, or have any questions regarding this event, please feel free to use the contact information below to reach the lupus study coordinator. Enjoy the rest of your summer.

Marcus R. Johnson
University of North Carolina - Chapel Hill
Thurston Arthritis Research Center
Work (919)966-2561 ext. 227

Toll-free: 1-877-462-9371

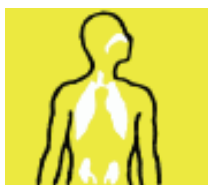
E-mail: marcus_johnson@med.unc.edu



**The National Wegeners
Granulomatosis Association
(WGA) elects a North
Carolinian as President of the
Board of Directors!!**

Dianne Shaw, who was elected President on April 9, 2005, helped develop the "What You Need to Know about Vasculitis" brochure that is sent out to GDCN patients diagnosed with ANCA-Vasculitis. Dianne was diagnosed with Wegeners' in 1995 and has served on the Board since 2002. She initiated the WGA advocacy effort and continues to push for national support of autoimmune disease research and increased awareness of vasculitis among health care professionals and the public.

Congratulations Dianne
and thanks for your
tireless work!



For more information on the WGA, 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 Kalino 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 Tracy Barrett, Project Director, at (919) 843-9256, or toll-free at (866) 827-2862 (please ask for the PAIRS study), or via email at: tmbarr@email.unc.edu.

ANCA DISCOVERIES: WHAT'S NEW WITH DNA

By Carla Nester, Pediatric Nephrology Fellow

Who would have thought that “used” mouthwash could be so useful! Researchers at the UNC Kidney Center have been using DNA taken from mouthwash specimens from ANCA patient volunteers to investigate possible genetic factors of the disease.

There have been many theories that genetics plays a part in small vessel vasculitis, and for years DNA collection has been requested from patients by drawing blood tests. A recent method of collecting DNA from a simple mouthwash specimen has made it possible to greatly increase the number of DNA specimens available, with much greater comfort for patients.

Research at UNC on mice showed that a gene called the Fc Gamma Receptor 2B (FCGR2B) might have something to do with lung involvement in ANCA disease. With an increasing number of DNA specimens available now, initial testing has now been started on ANCA patients to see how this gene might affect human disease. Early results seem to show that variations in this gene might signal a risk for developing ANCA lung disease with pulmonary bleeding and damage.

Initial results on the FCGR2B gene were presented recently at an international Symposium on ANCA disease in Heidelberg, Germany, and researchers from other countries may want to contribute DNA from their patients to extend the studies. It will take a large number of patient volunteers to get enough data to further assess the importance of these findings, so we thank all of you who have freely shared your mouthwash (and DNA) for the cause of understanding a bit more about ANCA disease!

NEW, MULTICENTER PATIENT REGISTRY FOR ANCA-ASSOCIATED VASCULITIS

A new, multicenter ANCA- vasculitis registry will soon start enrolling patients!

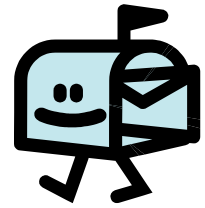
This effort is a multicenter of 18 research centers across North America and Canada, as part of the Glomerular Disease Trials Consortium (GDTC).

The registry will enroll patients and collect clinical data (from medical records). The data collected will be focused primarily on demographics, prior environmental and drug exposures, other medical conditions a patient may have in addition to vasculitis, and a listing of prior and current organ systems affected by vasculitis. More information will be outlined in the patient consent form, which will be sent out to eligible patients who have signed our long-term consent. The new registry will be an extension of the current GDCN registry. By enrolling patients from many institutions, the new registry will provide a foundation for the development and funding of new treatment trials as well as basic science and epidemiologic studies. Any new study would require a new and specific consent form, but this new, large registry will allow better estimates for recruitment and a launching pad for getting information about new studies to patients and their physicians.

This web-based, electronic ANCA registry has been approved by the UNC Institutional Review Board (IRB) and we are beginning to enroll patients. We are working with the other participating sites to obtain IRB approval so the consortium can proceed in establishing a registry of patients common to all the members of the Glomerular Disease Trials Consortium. Any patient information shared with the consortium from UNC will be de-identified, meaning the other participating sites will not have a patient's name or any other identifying information.

This registry will form the basis from which future studies, epidemiologic, descriptive or clinical, will be performed, and will hopefully give ANCA patients more opportunities to participate in clinical trials.

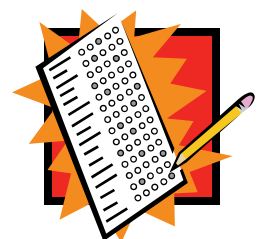
For more information, please contact study coordinator Jill Cooper at (919) 966-2561, x244; jill_cooper@med.unc.edu



Survey Alert!

Check your mailboxes for a green survey being sent out to all participants in the GDCN Registry. This survey asks for some background information on you and your family's types of jobs and education, and where you have lived. We think it is important to learn about the life experiences of patients with kidney disease, so that we might be more helpful to patients in the future.

Thanks in advance for your time and consideration!



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, or to enroll in any of these studies, please contact one of our Pediatric Study Coordinators:

Trevor Presler
919-966-2561 x.240
Toll-free 866-462-9371

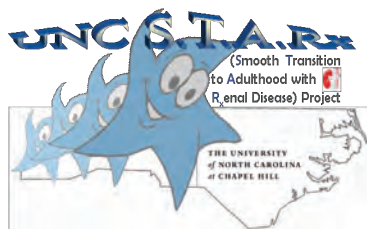
Ann Morris
919-966-2561 x.255
Toll-free: 866-462-9371

FONT STUDY

The FSGS Novel Therapies (FONT) Study for Focal Segmental Glomerulosclerosis (FSGS) began enrolling patients in July 2005. 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.



This NIH-Sponsored trial is being conducted to learn more about chronic kidney disease in children. Specific goals will examine characteristics predictive of a stable or progressive course, and to see how kidney problems affect a child's brain function, behavior, heart function, growth and general well-being. The study will enroll 540 children, ages 1-16, at 57 medical centers, including UNC Hospitals.



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.

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 173: Comprehensive Immunosuppressive Drug Coverage for Transplant Patients Act

Currently, kidney transplant recipients who qualify for Medicare only receive coverage for their anti-rejection drugs for 44 months after transplant. Anti-rejection drugs, if paid out of pocket, can cost upwards of \$20,000 a year. Patients who can't afford these drugs may not take them and run the risk of needing another kidney transplant. This bill seeks to lengthen Medicare coverage of immunosuppressants for transplant recipients beyond 44 months.

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

This expansive bill includes: Medicare coverage of kidney disease patient education services, better training of dialysis technicians, establishment of a committee to improve the quality of dialysis procedures, and supporting public and patient initiatives regarding kidney disease.

AN ADVOCATE FOR YOU:

THE PATIENT ADVOCATE FOUNDATION

The Patient Advocate Foundation (PAF) offers assistance to patients with specific issues they are facing with their insurer, employer and/or creditor regarding insurance, job retention and/or debt crisis matters relative to their diagnosis of life threatening or debilitating diseases. Any patient diagnosed with a chronic disease, which includes kidney disease, are eligible for PAF services. Their professional case managers and attorneys specialize in mediation, negotiation, and education, advocate on behalf of patients experiencing problems with access to care, job retention, and debt crisis.

The PAF seeks to empower patients to take control of their health care. Case managers work with patients to discover local, state, and federal programs that provide assistance for their individual needs. PAF has produced six major publications, several informational brochures, and several special sections devoted to certain health related topics to assist in this goal. Their case managers have also compiled a list of valuable resources that address several topics that you may find beneficial.

If you or someone you know needs assistance with their insurer, employer and/or creditor regarding insurance, job retention and/or debt crisis matters relative to their diagnosis of life threatening or debilitating diseases, please call the foundation at 1-800-532-5274, or go online: www.patientadvocate.org.



*Want to contact your State
Representatives and urge
support for
SB 173 and SB 635?*

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

The NephCure Foundation

15 Waterloo Avenue, Suite 200
Berwyn, PA 19312
Phone: 610-540-0186
Fax: 610-540-0190
Toll free: 1-866-NEPHCURE

Website: www.nephcure.org

Email: info@nephcure.org

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.

Wegener's Granulomatosis Association

P.O. Box 28660
Kansas City, MO 64188-8660
Phone: 1-800-277-9474

Website: <http://www.wgassociation.org>

E-mail: wga@wgassociation.org

The Wegener's Granulomatosis Association offers comfort and support to WG patients and families through education, awareness and research.

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.

Amyloidosis Support Network, Inc.

1490 Herndon Lane
Marietta, GA 30062

Website: www.amyloidosis.org

E-mail: info@amyloidosis.org

The Amyloidosis Support Network's primary function is to "link those affected by amyloidosis to further support resources" and increase public and professional awareness so that the disease can be detected earlier and properly treated.

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.

American Association of Kidney Patients

3505 E. Frontage Rd., Ste. 315
Tampa, FL 33607-1796
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.

IgA Nephropathy Support Group

Website: www.igan.ca

This is a web-based support group run by patients with IgA Nephropathy and also has information and useful links posted on the website.

Polyarteritis Nodosa (PAN) Research and Support Network

Website: www.pansupport.org

This website provides information, support, a patient chatroom, and a weekly Q&A session with an immunologist.

Lupus Foundation of America

2000 L. Street, N.W., Suite 710
Washington, DC 20036
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

345 MacNider Building, CB#7155
Chapel Hill, NC 27599-7155

Phone: 919-966-2561 ext. 263
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 disease that affect the
filters (glomeruli) in the kidney.*



www.unckidneycenter.org



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