

# Renal Health News

Serving Georgia, North Carolina and South Carolina ESRD Patients  
and Family Members

Issue 1  
2008



## WHO ARE WE? WHAT DO WE DO? WHAT DO WE DO FOR YOU!

Do you know who we are and what we do? The Southeastern Kidney Council is a nonprofit organization that contracts with the **Centers for Medicare & Medicaid Services (CMS)** for ESRD Network 6. ESRD Network 6 is part of a national system of ESRD Networks established by Congress in 1976 to help dialysis and kidney transplant centers achieve high standards of care for kidney patients. The Network 6 area includes Georgia, North Carolina, and South Carolina.

The Network goals are achieved by:

- Surrounding ourselves with Experts
- Collecting information on patients and facilities
- Identifying areas to help improve care
- Providing resources to help
- Problem Solving
- Listening to the community

The mission of the Southeastern Kidney Council is to improve the lives of people with or at risk for End Stage Renal Disease by promoting and advancing quality of care. We are able to fulfill our mission each day by assisting patients and facilities in the following areas:

1. **Information Management** – Network 6 supports more than 500 dialysis and transplant facilities. The Information Management staff are responsible for supplying forms, providing instruction, editing data, entering data, transmitting information to CMS and monitoring facilities for compliance.
2. **Quality Improvement** – Network 6 identifies opportunities for improvement in quality of care and works with facilities to bring about needed changes. This is accomplished by collecting patient and facility data, developing and conducting Quality Improvement Projects, providing education, technical assistance and tools to help patients and facilities improve quality of care.
3. **Patient Services** – Network 6 employs Nephrology Social Workers to work with patients, family members, facility staff, and the community with information, technical assistance, complaints and grievances, rehabilitation, education, and other ESRD related issues.

## Inside this issue:

- Patient Spotlight
- Transplantation
- Emergency Preparedness
- Dialysis Facility Compare
- Hypertension
- Treatment Options
- Community Events and Resources
- Fistula Cannulation
- Depression



## CALENDAR OF UPCOMING EVENTS

### GEORGIA

**March 8, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* Augusta, GA.

**March 13, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* Atlanta, GA.

**March 18, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* LaGrange, GA.

**April 10, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* College Park, GA.

**April 19, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* Savannah, GA.

**April 26, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* Macon, GA.

**May 8, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* College Park, GA.

**May 17, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* Valdosta, GA.

**June 5, 2008**—*National Kidney Foundation of Georgia KEEP Screening.* College Park, GA.

For more information on the *NKF of GA Kidney Early Evaluation Program Screenings*, contact John Riley at (800) 633-2339 or (770) 452-1539.

**June 29—July 5, 2008**—*National Kidney Foundation of Georgia Camp Independence.* A weeklong summer camp for children 6-18 years old diagnosed with kidney disease, on dialysis or the recipient of a solid organ transplant (kidney, heart, liver, lung). Contact Tracy Jenny for details (770) 452-1539 ext. 20 or (800) 633-2339.

**September 13, 2008**—*National Kidney Foundation of Georgia Kidney Walk.* Valdosta, GA. For more information and registration contact Cara McKinney at (770) 452-1539 ext. 11 or (800) 633-2339.

### NORTH CAROLINA

**March 8, 2008**—*National Kidney Foundation of North Carolina Free Kidney Screening.* Roanoke Rapids, NC. For more information contact Bill Haskins at (919) 622-4404 or Erin Pittman at (252) 535-4334.

**March 13, 2008**—*National Kidney Foundation of North Carolina Free Kidney Screening.* Greenville, NC. For more information contact Bill Haskins at (919) 622-4404 or Erin Pittman at (252) 535-4334.

**March 29, 2008**—*National Kidney Foundation of North Carolina Kidney Walk.* Research Triangle Park, NC. For information and registration go to [www.trianglekidneywalk.org](http://www.trianglekidneywalk.org).

### SOUTH CAROLINA

**October 16, 2008**—*National Kidney Foundation of South Carolina Patient Symposium.* Charleston, SC. For more information, contact National Kidney Foundation of South Carolina at (803) 799-3870 or (888) 848-5277.



## Spotlight on Patients

A few days ago I went to the funeral of one of the people I attend dialysis with. It started me to thinking about the lives of us on these machines that

### THE MACHINE

Submitted by *Lucille C. Butler, Decatur, GA*

keep us living. This young man had a lovely home going service. He was well spoken of by his friends and family. They reminisced about the many good times they had doing so many fun things in their childhood. They told about the times he figured out things they could not, and did them in such a simple way they believed he was a genius. They spoke of how even tempered he was and how he never showed anger. He was an interesting person to have known and I'm glad I got to know him, although briefly, while we sat across from one another hooked up to the machine.

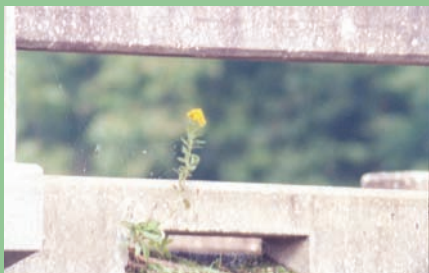
In the year and a half I have been on the machine, I have never been able to come up with an affectionate name for it. Maybe it's because we don't know from day to day which machine we will be on. We cannot dismiss the importance of the machines. In our lives, we are still human beings with families who love us and with things in this beautiful world that interest us. We are not like ships passing in the night. However brief we are in one another's presence, I believe we should get to know one another. It will make our lives richer. We can become so preoccupied with our illness that we do not look around and see how interesting people are.

Let us live with the machine but not become impersonal like the machine. It is doing the job it was created to do. We are God's creation and our job is to love and care about one another. Whether I have to live three days on a machine or not, I am determined to keep my humanity.

## PHOTOGRAPHY REFELECTIONS

Submitted by *Kyle D. Rodgers, China Grove, NC*

I'm sending some pictures – one of a water bird I like and a bridge and a flower on the bridge. On weekends, and any other time I get, I take pictures of wildlife. If I can find where there aren't any people to mess it up. It is getting harder to find places that there are no people. So most animals have to learn to live with people. So, what gets me is that the flower is growing on a bridge and living without a lot of soil and water and with cars and things running next to it. So it found a way to live and beat out the fact that it should not be there and be living. Even a spider lives with it. So if we learn anything from this flower it is dialysis is not the end for us, but just the next step in a life. A new life and a better life.



## TRANSPLANTATION Q&A

Submitted by *Lynn W. McCoy RN, CNN, Pediatric Nephrology Care Coordinator, Division of Nephrology and Hypertension, Chapel Hill, NC*

Considering whether or not renal transplantation is right for you is a very personal decision that patients and their families must consider carefully. There are many members of your local healthcare team that can support you through the decision making process. Once you've decided to pursue renal transplant as a treatment for your kidney failure, your transplant team will join your local healthcare team in providing additional support specific to transplant. The following are commonly asked questions and answers you might consider as you pursue transplantation:

**1. Does my insurance require a “special” referral for me to be evaluated for a kidney transplant?**

*Some insurance DOES require your Nephrologist to obtain a referral BEFORE any appointments for evaluation are made. Check with your insurance directly or speak with someone at your employer's Human Resources office.*

**2. Can I choose which transplant center I go to?**

*Yes, unless your insurance requires your transplant evaluation and surgery occur at a particular center. Again, it's important to contact your insurance company directly or speak to a representative in your HR department about the specifics of your coverage. Some insurance companies will assign you a special transplant case manager and this individual can be very helpful in addressing these and other transplant related insurance issues.*

**3. When will my medical records be sent to the transplant center for review and consideration for evaluation? How long before I know whether or not I can be evaluated?**

*Your Nephrologist and dialysis staff can tell you the status of the “paperwork” that goes to the transplant center. They also have experience with the various transplant centers in your area and can give you a reasonable estimate of when you might know something. They can also provide you with a contact at the transplant center if you want to personally confirm your paperwork was received.*

**4. Are there educational opportunities I can access before beginning the transplant medical evaluation?**

*Your dialysis staff, social worker and Nephrologist can help provide you with a variety of resources about transplantation. The transplant center you have been referred to also has resources such as written material, videos and or patient classes to help you through the learning process. There's lots of information to be learned, and no one expects patients to learn it all at once. If you obtain information from the internet it is wise to carefully consider the source. If in doubt, the dialysis staff, Nephrologist and transplant center can verify sources for you.*

**5. What is the time frame to complete the transplant evaluation for a patient with a diagnosis similar to mine?**

*Your transplant center will be able to provide an overview of what you might expect during your evaluation, including the actual testing to be done and the implications of various results, i.e. whether additional testing required, what would exclude you as a recipient, etc.*

**TRANSPLANTATION Q&A CONTINUED****6. When will I know my evaluation testing is complete and what the outcome is?**

*Your transplant center will have the final word on when your evaluation is complete and whether or not you have been cleared to proceed with transplant surgery or listing for a deceased donor transplant.*

**7. If I have possible donors how and when can they find out if they can donate to me?**

*The live donor evaluation process begins with identifying those individuals who are willing to consider donation. Very basic requirements include that they be in good overall health and of a compatible blood type. Your transplant center will provide potential donors with detailed information about the donor evaluation and donor surgery. A separate healthcare team will care for the potential donor throughout the process.*

**8. If I do not have a live donor and have to be on the waiting list for a deceased donor is there anything I should know while waiting?**

*Stay in contact with your transplant center on a regular basis. Let them know if you have any changes in your health, undergo surgeries, have a change in type of dialysis your receiving, change in insurance coverage or change in your contact information.*

**9. How long is the transplant evaluation good for? Does it ever expire?**

*Evaluations or portions of it are typically good for a year to eighteen months. The evaluation will need to be updated periodically based on your current medical diagnosis and any new medical issues that may arise. When and how your evaluation will be updated may also depend on recommendations from the transplant team and your local Nephrologist.*

**10. Do I have to have a transplant just because that's what everyone says I should do?**

*No, the final decision to proceed with transplant is a choice you have to make for yourself. It is a treatment just as dialysis is a treatment and has the potential for good outcomes, as experienced by many who choose transplant. There are also risks that must be considered carefully. Your Nephrologist, dialysis staff and the transplant center will support you regardless of the decision you make.*

**Facts About the Pneumonia Vaccine that Every Person Needs to Know!**

- About one out of every 20 people who get pneumonia dies from it.
- Pneumococcal disease is caused by bacteria. It can lead to serious infections of the lungs (pneumonia), the blood (bacteremia) and the covering of the brain (meningitis).
- The pneumococcal vaccine protects against 23 types of pneumococcal bacteria. A one-time shot usually gives you protection from pneumococcal disease. In some instances, you may need a second shot after five years—ask your doctor.
- Everyone 65 years of age or older should receive the pneumococcal shot. People who have long-term health problems such as kidney, heart, lung, liver, diabetes, or sickle cell disease should get this shot. Anyone who has a disease or condition that lowers the body's resistance to infection should also receive the injection.
- The pneumonia vaccine can be received any time during the year. It usually begins protecting you within two or three weeks of getting the shot. You can get it the same time you get your flu shot!
- Medicare Part B pays for the pneumonia vaccine.



## WHAT IS DEPRESSION?

Submitted by *Mark Meier MSW, LICSW, Chief Executive Officer, Creative Workplace Solutions, Minneapolis, MN*

Have you ever thought that since you live with a chronic illness, such as kidney disease it is normal you feel down or depressed most of the time? Do you find that you have lost hope about the future? Do you feel resigned to not experiencing happiness or enjoying activities that you once found enjoyable ever again? If you answered yes to any of these questions then this article is important for you.

### **Depression vs. The “blues”**

What is true for most individuals, including those with chronic illnesses, is that we all experience bad days, get the “blues”, or experience feelings of sadness that are associated with the normal trials of life such as the death of a loved one. However, depression is a significantly different issue that impacts about 10% of the U. S. population during any given year and if you are suffering from a chronic illness the likelihood of you experiencing a bout of depression goes up.

### **What Is Depression?**

Depression, unlike the “blues”, is a medical condition that when left untreated can get worse and can also complicate the management of any other disease or illness you might be living with. Depression is characterized by symptoms which include:

- Feeling down or depressed most of the time
- A loss of interest or pleasure in previously enjoyed activities
- Changes in appetite with associated weight gain or loss
- Sleep difficulties, such as sleeping too much or difficulty staying asleep
- Unexplained feelings of guilt or worthlessness
- Psychomotor agitation or retardation
- Diminished ability to think or concentrate, difficulties making decisions
- Fatigue or loss of energy nearly everyday
- Recurrent thoughts of death or suicide

Depression, unlike the normal periods of sadness we all feel, also tends to last for weeks on end and despite your best efforts you cannot will your depression away. Depression has a both a chemical and biological basis and it is not a sign of a personality flaw or a weakness.

### **Am I Depressed?**

Admitting to yourself that you are suffering from depression is difficult and admitting it to others can be even more difficult. However, if the symptoms above sound like issues you have been experiencing it is important to begin speaking with a trusted healthcare professional about your concerns. One of the greatest tragedies of untreated depression is suicide. The data supports that most individuals who are suffering from depression will not attempt suicide, but we do know that untreated depression is the number one leading cause of suicide. When an individual commits suicide the impact left on family members, friends, and others is profound and lasting. Depression is a treatable condition, but only if you talk with others about your concerns.

### **Treatment for depression**

For individuals with mild depression it is possible that some lifestyle changes (e.g. exercise, diet, proper sleep) might be adequate to reduce the feelings of depression. For those who are suffering from more serious depression additional treatment strategies are available.

### ***WHAT IS DEPRESSION? CONTINUED***

Despite many people's belief that antidepressants are being overused in this country, the National Institute of Health (NIH) suggests only about 25% of all people suffering from depression are being adequately treated with medication and counseling. Antidepressants are frequently an effective and time-limited approach to treating your depression. Critical to having an antidepressant work properly is your willingness to take the medication as prescribed, take the medication for a reasonable length of time (generally 1 year minimum), and actively monitor the medications effectiveness because some people respond better to certain types of antidepressants than others.

In addition to taking an antidepressant other life changes must be considered as well. The research is clear that individuals who are suffering from depression who take an antidepressant and who engage in some counseling or therapy will have better outcomes than those who just take an antidepressant or just attend counseling. Living with kidney disease is a difficult proposition and attending counseling to learn how to cope with your illness and your depression could have many positive benefits for you.

### **Conclusion**

Depression is a very real and complex medical condition which if left untreated can cause profound physical and emotional problems. Having a bout of depression is not a sign of weakness or a personality flaw, but rather something that upwards of 30%-40% of all individuals with chronic illnesses deal with. The use of an antidepressant, counseling, and adjustments in your lifestyle can help you to beat your depression and gain back your hope and interest in life. If you are concerned about whether or not you might be depressed, take that important first step toward recovery and talk to a healthcare professional about your concerns.

## **SURF THE WEB**

Take time to explore the following web sites to assist you in researching resources. Most libraries have computers with free Internet access. All you have to do is schedule your time and keep it limited to the time period designated by the library.

### **[www.GovBenefits.gov](http://www.GovBenefits.gov)**

[www.GovBenefits.gov](http://www.GovBenefits.gov) is the official benefits web site of the U.S. Government and has information for more than 1,000 Federal and State administered benefit and assistance programs. The web site is a partnership of Federal agencies and allows *anyone* to find and share information about many benefit and assistance programs. Some of the targeted areas include programs for disaster relief, education, childcare/support, food/nutrition, health care and more. The web site has an online screening tool which is free, easy-to-use and completely confidential.

### **[www.care.com](http://www.care.com)**

[www.care.com](http://www.care.com) is an Internet source of care options for every family member, from elderly parents to children and even pets. The Care Directory provides a comprehensive listing of resources by state in seven categories: housing resources, transportation resources, home care, end-of-life care, legal resources, and financial planning and management. The web site has caregiver listings, articles and advice for seniors, their families and their Care givers.



**KNOWLEDGE IS POWER: WHAT ARE MY OPTIONS?**

Submitted by *Missy Parks BSN, RN, CNN, Nurse, Consumer Committee Member, Union, SC*

Before making any life altering decision, we almost always weigh the “pros” and “cons”. Countless hours are often spent researching all the options so that an educated decision can be made. However, I’ve come to realize that this principle doesn’t always apply to patients who have been diagnosed with End Stage Renal Disease (ESRD). There are several reasons why patients do not always make “informed” decisions regarding their care.

One question that has become common in the outpatient dialysis setting is, “How long will I have to do this dialysis?” The first time a patient asked me this question I was completely taken back by it. It was at that moment that I asked myself, “Where have healthcare professionals gone wrong?” I realized one of the main reasons patients are not making informed decisions is lack of education. I am pleased to say efforts are being made to correct this. One of the newest topics surrounding Chronic Kidney Disease (CKD) is “Pre-End Stage Education”. This concept refers to patients being educated about impending renal failure before they are diagnosed with ESRD.

Unfortunately, the more common scenario seems to be those patients who begin to exhibit signs and symptoms of kidney disease, but fail to seek medical care. Eventually they become very sick, requiring admission to the hospital. At this point, the patient can barely grasp the concept of their new diagnosis, much less comprehend information regarding treatment options. Many times this scenario requires more emergent interventions, eliminating the possibility of the patient having the time to research and discuss treatment options with their physician.

Ideally, patients who are being monitored by a Nephrologist in the office, will begin receiving education regarding their disease process. This should include information about progression of the disease and possible treatment options. There are 5 Stages of Kidney Disease. Once a patient is diagnosed as having End Stage Renal Disease (Stage 5), a decision must be made regarding which treatment option is best for the patient. Available treatment options include: 1) Hemodialysis 2) Home Hemodialysis 3) Peritoneal Dialysis and 4) Transplantation. The newest trend is home hemodialysis. This treatment modality offers patients, who are not candidates for peritoneal dialysis, another option for doing dialysis at home.

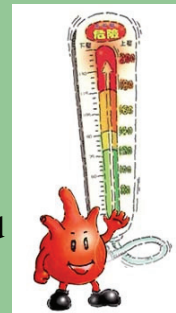
As efforts are being made to provide patients with more early education regarding their disease process and treatment options, the success of the program depends largely on participation from the patients. Patients should never take a “back seat” when it comes to the planning of their care. They should be familiar with the risk factors for developing kidney disease, as well as early warning signs. Diabetes and hypertension are the two leading causes of renal failure. Therefore, routine medical exams and check-ups are recommended for those patients who are at risk for developing chronic kidney disease. Hopefully, patients who are already living with CKD will join in the efforts of health care professionals to educate others. For those patients who have already been diagnosed with ESRD, I encourage you to explore all available treatment options. Ask your doctor for more information on alternate treatment options. Patients should always take an active role in their treatment planning. Knowledge is power. Don’t be afraid to ask, “What are my Options”?

**March is National Kidney Month!**  
**March 8—World Kidney Day**

## HYPERTENSION, WEIGHT GAIN, & THE HEMODIALYSIS PATIENT

Submitted by *Merrill Hicks MD, Nephrologist, Consumer Committee Member, Thomasville, GA*

Lots of emphasis is placed on weight gain in the dialysis arena (that is, water or fluid weight gain between dialysis treatments), with little emphasis on *why* this is important, other than avoiding hospital admissions because of fluid build-up in the lungs (otherwise known as acute congestive heart failure). Particularly in dialysis patients, hypertension (blood pressure *before dialysis* of more than 140/80) results from retaining too much fluid. The first way to treat high blood pressure is to find and maintain the right body weight. Often, high blood pressure will persist even when there are consistent small fluid gains between treatments. At this point the blood pressure may be maintained by overdeveloped muscles of the heart or arteries (due to high blood pressure over a long period of time) may require use of medicines. But, determining and maintaining the “dry” weight remains the main way to control high blood pressure.



Control of high blood pressure begins with control of weight gain between treatments and particularly over the weekend. The successful dialysis patient makes fluid control a priority by avoiding salt and other high sodium seasonings (such as Accent), by limiting fluid intake through constant measurements, by using frozen fruit to ‘cool’ your thirst, and particularly focusing on *modest weekend weight gain* as the key to blood pressure and weight control.

Basically, if there is a big weekend weight gain, it takes the whole week to get back down to ‘dry weight’, with higher blood pressure as long as extra fluid is on board. If there is any time to measure and limit your fluid intake, the weekend is the time to do it; if there is any time to avoid salt or sodium intake, the weekend is the time to do it. The target blood pressure of 140/80 or less (before dialysis) is reached by close attention and hard work, particularly on the weekend.

In 1991 the Charras group from Tassin, France published the best yet hemodialysis survival results and showed that these results were due to good weight control which resulted in good blood pressure. Of course, this group dialyzes their patients *8 hours per treatment*, which allows pulling off enough fluid per treatment in order to reach dry weight, consistently. Since 8 hour treatments (or, treatments more than 3 times weekly) are not possible for most American dialysis patients, extra effort to control weight & blood pressure is necessary. Ultimately, good blood pressure control results in less cardiovascular side effects—less strokes, less heart failures or heart attacks, less peripheral vascular disease (including less amputations), and less dementia from mini-strokes—these are the reasons for focusing on limited fluid gain and blood pressure control. Be sure you know what your blood pressure is every time you start dialysis!



## VOCATIONAL REHABILITATION—THE GOAL IS GAINFUL EMPLOYMENT

- Are you satisfied with your current level of activity because of ESRD?
- Have there been any changes in your employment status because of ESRD?
- Are you interested in pursuing new educational interests?
- Do you need assistance with your vocational and educational goals?

Many people who are disabled question their ability to be an effective employee and there are many physical barriers in the workplace. In 1973, the United States legislature passed the Vocational Rehabilitation act of 1973 Title V, which was designed to fight against discrimination against people with disabilities. Vocation Rehabilitation (VR) is a program developed to assist eligible people with disabilities to prepare for, achieve and maintain competitive employment and eligibility through vocational and educational opportunities. A vocational counselor can help you explore the options available to you in reaching your vocational or educational goal.

Additional services may include assistance for transportation, childcare, books, and other school supplies. Services can include the purchase of an artificial limb if the client meets financial and other eligibility criteria.

*Employment: A Kidney Patient's Guide to Working and Paying for Treatment* is a free resource offered through Life Options. Be sure to explore the Life Options web site at: [www.lifeoptions.org/catalog/booklets](http://www.lifeoptions.org/catalog/booklets). *Working While Disabled* is a free publication offered through the Social Security Administration, which addresses the effects of working on benefits. Explore the Social Security website at [www.ssa.gov](http://www.ssa.gov).

If your disability is interfering with your ability to continue your current job you may be eligible for Vocation Rehabilitation services. Ask your facility Social Worker about a referral or refer to the contact information below:

### North Carolina Vocational Rehabilitation

Web site: <http://dvr.dhhs.state.nc.us>

Phone: (919) 855-3500

TTY: (919) 855-3579

### South Carolina Vocational Rehabilitation

Web site: [www.scvrd.net](http://www.scvrd.net)

Phone: (803) 896-6500

Toll-free: (800) 832-7526

TTY: (803) 896-6553

### Georgia Vocational Rehabilitation

Web site: [www.vocrehabga.org](http://www.vocrehabga.org)

Phone: (404) 486-6331

Toll-free: (866) 489-0001

TTY: (404) 486-6333



**Improving Your Quality of Life: Rehabilitation Resources**

Rehabilitation means restoring you to stable health, a positive outlook, and activities you enjoy.

Life Options has developed valuable resources for people with Chronic Kidney Disease. This information is based on the "Bridges to Rehabilitation: The Five E's"

- Encouragement
- Education
- Exercise
- Employment
- Evaluation

Visit the Life Options Web site at <http://www.lifeoptions.org/catalog/catalog.php?prodCat=booklets> to download this information on rehabilitation.

**The Southeastern Kidney Council has a toll-free number for patients and their family members:**

**1-800-524-7139**

D A K S D M R N E E E C Y K F  
 A I I H O W E O X N R H T L M  
 V N D I E P H I E I A F I S R  
 Q O N N M A A S R H P I N S E  
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ACCESS  
 CANNULATION  
 COMMUNITY  
 CONSUMER  
 EMERGENCY  
 EXERCISE  
 FISTULA  
 HYPERTENSION  
 KIDNEY  
 MACHINE

PATIENT  
 PNEUMONIA  
 PREPARE  
 REHABILITATION  
 RENAL  
 SHINGLES  
 TRANSPLANT  
 VACCINE  
 VASCULAR  
 VOLUNTEER


**WANTED: VOLUNTEERS  
 FOR NKF-GA KEEP 2008!**

**The National Kidney Foundation  
 of Georgia's  
 Kidney Early Evaluation Program  
 (KEEP) NEEDS YOU!**

The NKF-GA are looking for doctors, physician assistants, nurses, medial assistants, phlebotomist and social workers to help STOP kidney disease before it starts. FREE screening to members of the population who are at HIGH RISK for CKD are provided.

Visit their website at [www.kidneyga.org](http://www.kidneyga.org) to view their community calendar or get more information about the KEEP Program.

Free t-shirts and cool stuff for all volunteers! *To sign up or for more information, call John Riley at (800) 633-2339, ext. 25.*



## EMERGENCY PREPAREDNESS REMINDERS

**Are you prepared for emergencies?** The federal regulations require all dialysis facilities to have a written emergency disaster plan. It is equally important for all patients to have their own personal emergency disaster plans. Certain types of disasters may be more common in certain areas and need to be planned for. However, an all inclusive emergency disaster plan would include disasters such as, power outages, mold, gas leaks, terrorist threats, and drought.

Consider the following steps to help you **prepare** for an emergency:

1. Gather and carry important medical information. Putting important medical information in a zip-lock bag will help to keep it protected. You may want to give a copy to your caregiver or family member. Complete a *Patient Emergency Tips card* and enclose it in the zip lock bag.
2. Ask your facility about how to find out about alternative arrangements for treatment. Having a current list of dialysis facilities in an area outside the emergency may help to locate a dialysis treatment.
3. Prepare an emergency stock of supplies, food, water and medicines. Put a list of your current medications in the zip lock bag. Prepare an emergency box to include food, water, radio with batteries and medications for a week.
4. Know what diet to follow if your dialysis must be delayed. Ask your dietitian for assistance with education about an emergency diet. Fluids may have to be reduced and the types of foods may need to be changed to fit the situation.
5. Make sure your dialysis clinic has your current address, phone number, and backup contacts.
6. Know your local official radio or television emergency broadcast channels. You can receive important community information about the disaster and your dialysis facility is in operational status.
7. For priority consideration in the event of a power outage, contact your local power company to notify them that you are a dialysis patient.
8. Have a list of your local Emergency Preparedness Agency contacts. Ask your facility Social Worker about this information.

Read the *CMS publication number 10150*, “Preparing for Emergencies: A Guide for People on Dialysis”. This booklet covers many helpful topics such as:

- Helpful Tips in an Emergency
- Steps to Prepare for an Emergency
- Carrying medical information
- Making alternative arrangements for treatment
- Preparation of an emergency stock of supplies, medicines, food and water
- Emergency diets
- How to disinfect water
- If you are on a dialysis machine in an emergency

The most important element of an emergency disaster plan is **preparation**. Planning and preparing for a disaster is an on-going commitment and knowing how to respond ahead of time may reduce confusion and save lives. If you have any questions or concerns. Please contact the Network office at (800) 524-7139 or (919) 855-0882.

Here is a handy way to remember important points to remember in the event of an emergency:

### READY

**R is for Rx (medications).** Keep a list of all medicines you take and always have some on hand. Keep the list in a zip lock bag.

**E is for E.R.** Go to the emergency room if you have serious problems. Keep a current list of your medical issues with you. Keep the list in a zip lock bag.

**A is for access to people and places.** Make a list of phone numbers most important to you. Keep the list in a zip lock bag.

**D is for diet and liquids.** Keep safe supplies on hand.

**Y is for You!** Make a plan with family, friends and neighbors to stay safe.

**DIALYSIS FACILITY COMPARE: [WWW.MEDICARE.GOV/DIALYSIS](http://WWW.MEDICARE.GOV/DIALYSIS)**

Dialysis Facility Compare is a web site hosted by the Centers for Medicare & Medicaid Services (CMS) that gives information to consumers about Medicare-certified dialysis facilities in order to assist them in choosing a dialysis facility. Dialysis Facility Compare provides characteristics as well as quality measures for each facility. The characteristics are updated monthly and include the following:

- Address and phone number
- Date of initial Medicare certification
- Whether or not there are shifts starting after 5:00 pm
- Number of treatment stations
- Types of dialysis offered (hemodialysis, PD, home hemodialysis)
- Type of facility ownership (profit or non-profit; corporate or independent)

The quality measures obtained from the Medicare billing database are updated periodically and include:

- Percent of patients with a URR  $\geq$  65%
- Percent of patients treated with Epogen with a hematocrit  $\geq$  33%
- Patient survival information (better than expected, as expected, or worse than expected)

We encourage you to utilize this website. It can be very useful to patients planning transient treatment or more permanent moves. If you need assistance with this information, call the Network office at (800) 524-7139 or (919) 855-0882.

**NEWS FROM THE GEORGIA ASSOCIATION OF KIDNEY PATIENTS (GAKP)**

Submitted by *George Harper M.Ed, Ed.S, Rome, GA*

GAKP continues to work to pass a dialysis technician certification bill for Georgia. SB 57, sponsored by Senator Renee Unterman (R-Buford), a former nephrology nurse, passed the Georgia Senate but failed to report out of the House Rules Committee in the final days of the 2007 legislative session. However, it is still alive and will come up again in the 2008 legislative session. SB 57 certifies dialysis technicians and places them under the supervision of the Georgia Board of Nursing. Key to the bill is a requirement that technicians pass a nationally recognized certification exam.

The bill is supported by GAKP and the Kidney Foundation, but there are interests who oppose the bill based in part on costs. The cost of the program would consist of a one-time test fee of \$125 per technician and an approximate \$40 annual state certification fee.

GAKP is a grass-roots patient organization founded by and for patients and dedicated to advocacy, support, and education of Georgia kidney patients and their families. GAKP believes that patients are their own best advocates.

GAKP meets at 2:00 pm on the third Sunday of January and every other month thereafter, at Piedmont Hospital, Building 1984, Classroom 1 in Atlanta. Family memberships of \$10.00 per year support our work and may be paid to GAKP and mailed to Boo Hall, Treasurer, 28 Velma Drive, Newnan, Georgia 30263. For more information, contact Joel Kollin, President, at 770-392-7958 or [jkollin@comcast.net](mailto:jkollin@comcast.net).

## YOUR ROLE IN AV FISTULA CANNULATION

Submitted by *Lynda K. Ball, RN, BSN, CNN, Quality Improvement Director, Northwest Renal Network*

It is important to take an active part in your vascular access care. Even if you don't insert your own needles (cannulate), it is important for you to understand what is going on. Below are some tips for making your AV fistula last for a very long time.

**Assess Your Access:** At least two times a day, check your access to make sure it is working (patent). Place two fingers over the site where your surgery was (anastomosis), and feel for one of two sensations, called a thrill – a purring like a cat, or a vibration like a vibrator. A thrill should never feel like a bass drum thumping because this is a sign that there is a problem with your fistula, and you need to tell your nurse.

**Signs and Symptoms of Infection:** There are several clues that will tell you that your AV fistula could be infected. Always look for redness of the skin over your fistula or drainage coming from your fistula. Use the back of your hand and feel if the skin is warmer over your fistula than your other arm. Taking your temperature before dialysis will also help the staff determine if you have an infection.

**Exercise Your Access:** Starting one week after access surgery, you should start to exercise your arm to develop your new fistula. Exercise is good for small, problem fistulas too. If your AV fistula is in your lower arm, squeeze a small rubber ball several times a day for five minutes at a time. If your AV fistula is in your upper arm, hold on to a soup can or bottle of water and do curls - bending your arm up slowly at the elbow, then stretching it out. Even though it is the pressure of the blood flowing through your fistula that makes it big enough for cannulation, exercise can help.

**Washing Your Access:** The nurses and technicians may ask you to wash your arm before coming to your chair. This helps to reduce the amount of staph, a bacteria that is on everyone's skin. Staph is okay on your skin, but can make you very sick if it gets into your bloodstream. Dialysis patients have a lot on their skin, and even in their noses, so it is important to wash some away just before cannulation.

**Learn to Self-Cannulate:** Many people are afraid of needles, myself included, because they can cause pain. If you have had needles inserted into your skin before, you know that depending on who inserts your needles, it may hurt more or less. This has to do with their technique, or how they were trained to insert needles. The best thing about putting in your own needles is you take the guesswork out of which cannulator will show up. Patients are better able to feel where the fistula is. Whether it is your concentration or your technique, you will find self-cannulation is a lot less painful and stressful, especially if you choose to use the Buttonhole Technique.

**Three Strikes and You're Out!** Remember this tip, no one should attempt more than three needles sticks in your access. Two is normal, a third if there is a problem – but no more. Ask them to have another cannulator come and insert your needle. Please don't be afraid to speak up, it's your lifeline, and you are the caretaker.

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*The articles in this newsletter do not necessarily reflect the views or  
opinions of the Southeastern Kidney Council.*



## **Southeastern Kidney Council, Inc.**

1000 St. Albans Drive, Suite 270

Raleigh, NC 27609

Phone: (919) 855-0882

Toll-Free for Patients Only: (800) 524-7139

Fax: (919) 855-0753

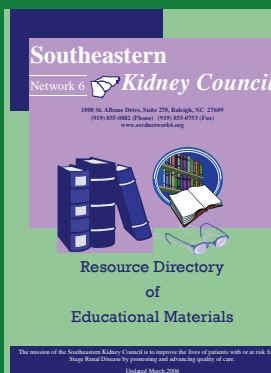
E-mail: [info@nw6.esrd.net](mailto:info@nw6.esrd.net)

Web site: [www.esrdnetwork6.org](http://www.esrdnetwork6.org)



**Do you have a story, poem, or renal friendly recipe that you would like to share with other patients and family members?**

Send to: Southeastern Kidney Council  
Attention: Amy B. Williams  
1000 St. Albans Drive, Suite 270  
Raleigh, NC 27609



## **Resource Directory of Educational Materials**

Updated January 2008

Would you like to learn more about kidney disease, dialysis, vascular access, self-care, nutrition, diabetes, high blood pressure, transplants, peritoneal dialysis, other treatment

options, and much more? The Southeastern Kidney Council has compiled a list of educational resources that are available throughout the renal community into one book, titled the Southeastern Kidney Council Resource Directory.

This directory is updated periodically and is available for your viewing and can be downloaded via our web site at: [www.esrdnetwork6.org/publications/resource-directory.html](http://www.esrdnetwork6.org/publications/resource-directory.html).

For questions or more information, call the Network office at (919) 855-0882 or (800) 524-7139.

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Raleigh, NC 27609

## **HAVE YOU MOVED?**

If you have recently moved or changed your phone number be sure to tell someone at your facility.

Also, when you provide your new information, remind the staff to contact the Southeastern Kidney Council with the changes or call yourself.