Southeastern
Network 6
Kidney Council, Inc.

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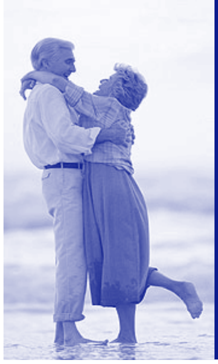


Renal Health News

A Newsletter for ESRD Patients

The mission of the Southeastern Kidney Council is to improve the lives of patients with or at risk for End Stage Renal Disease by promoting and advancing quality of care.

Southeastern Kidney Council – ESRD Network 6 – We Are Here 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 goals of the ESRD Network program are:

- Improve data reporting, reliability, validity between ESRD providers, ESRD Networks, and CMS
- Establish and improve partnerships between state surveyors and Quality Improvement Organizations
- Evaluate and resolve grievances
- Improve quality of care and quality of life for ESRD beneficiaries

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

Toll-free number for patients and their family members:
1-800-524-7139

Website:
www.esrdnetwork6.org

The mission of the Southeastern Kidney Council is to improve the lives of patients with or at risk for End Stage Renal Disease by promoting and advancing quality of care. We are able to fulfill this 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 two 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.

Newsletter Update: Renal Health News on the Web

The *Renal Health News* is a bi-annual publication for ESRD patients and family members. As society enters the electronic age we are doing our part to keep up with technological advances. In the past this publication has been mailed to each of the 35,000+ ESRD patient's homes in Network 6. Going forward we will be mailing multiple copies of this publication to the ESRD facilities and posting the newest edition to our website at www.esrdnetwork6.org.

Vocational Rehabilitation

Have you considered returning to work or going back to school? Your local Vocational Rehabilitation office may be able to assist you. Vocational Rehabilitation services provide individuals with disabilities opportunities for independence through employment and education. A Vocational Rehabilitation counselor can help you explore the options available to you in reaching your vocational or educational goal. Local offices often have relationships with community employers and schools or colleges to best place individuals in an ideal setting. Additional services may include assistance with transportation, child care, books and other school supplies. Ask your facility social worker about a referral, or to contact your local office, refer to the contact information below:

- North Carolina: http://dvr.dhhs.state.nc.us ~ (919) 855-3500
- South Carolina: http://www.scvrd.net ~ (803) 896-6500
- Georgia: http://www.vocrehabga.org ~ (866) 489-0001

Dialysis Facility Compare ~ www.medicare.gov/dialysis

Did you know that there is a website that will give you information about Medicare-certified dialysis facilities? Did you know that you could use this information to assist you in choosing a dialysis facility? The website is called Dialysis Facility Compare. It is hosted by the Centers for Medicare & Medicaid Services (CMS). 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 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 informative website. It can also be very useful when you are planning transient treatments or permanently moving. CHECK IT OUT!

Vascular Access Options

arteriovenous **FISTULA FIRST**
AVF — The first choice for hemodialysis

There are three types of vascular accesses for hemodialysis patients: fistulas, grafts and catheters. For most patients the preferred access is a fistula. Studies have shown that patients with a fistula live longer and have fewer hospital admissions than those with grafts or catheters.

- Arteriovenous Fistula (AVF) is created surgically by connecting an artery and a vein under the skin to allow sufficient blood to flow for hemodialysis. The procedure is usually performed on an outpatient basis. The patient will need to perform hand exercises to help increase the blood flow. Larger and stronger veins will develop making needle insertion easier. Fistulas take approximately 6-8 weeks to mature. Fistulas are the preferred type of vascular access because of less complications and the ability to obtain good blood flow.
- Grafts are surgically created by joining and an artery and a vein with a synthetic tube. The tube is tunneled under the skin and attached to an artery and a vein. The graft can be used for dialysis in approximately 3-4 weeks. Grafts may become infected and clot. This will require further medical intervention. When the graft fails, venous mapping and ultrasound can be ordered to see if your veins will accept a fistula.
- Catheters are plastic tubes that are inserted into the heart via a vein. The catheter tubing has 2 ports that allow for access to the patients circulatory system. One port will take the blood to the dialysis machine and the other returns the blood to the patient. Catheters are usually used when the patient does not have a permanent access in place or when the permanent access does not work well or fails. A catheter is a temporary access. Various complications of a catheter include increased infection, blood loss, and poor blood flow rate during dialysis.

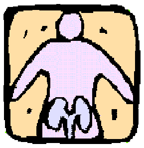
Are You Prepared for an Emergency?

In the aftermath of severe weather across the Southeast, the Southeastern Kidney Council encourages all patients to prepare themselves for the possibility of a disaster. All types of disasters should be taken into consideration. Emergencies caused by severe weather or disasters can happen with or without warning. It is important to be prepared! The following are a few steps to consider when preparing for an emergency:

- Know your dialysis facility's emergency plan
- Keep your emergency contact information up-to-date
- Keep important personal papers with you (identification, insurance cards, etc.)
- Keep a current list of your medicines and allergies
- Remember that your vascular access is to be used only for dialysis
- Prepare an emergency stock of supplies, medications, and food
- Know your emergency diet
- Always have a back-up plan

For more detailed information on preparing for emergencies, the Southeastern Kidney Council has various resources available including the booklet "Preparing for Emergencies: A Guide for People on Dialysis" (available in English and Spanish). This booklet explains helpful tips, how to prepare, how to disinfect water, and more. For a copy of this booklet or other disaster preparedness materials, contact your facility social worker or the Network office.

Transplantation is a Treatment—Not a Cure



Many people think that when they get a kidney transplant they will never have to face dialysis again. Education of the patients, families, and caregivers to reassure and separate facts from myths is invaluable as a step for the consideration of transplantation. Some patients may fear the return to dialysis treatments and allow this to keep them from pursuing transplantation. Although the transplant patient always has the possibility of rejection and the return to dialysis treatments, the benefits of a transplant can outweigh the negative aspects of this reality.

The transplantation process is fairly standard between transplant centers. However, there may be some differences in policies and procedures. As a patient you are encouraged to ask questions. **It is the patients' right and responsibility to ask questions. Here is a sample of important questions that you can ask your healthcare team:**

- Am I medically suited for a kidney transplant?
- If I have a medical problem keeping me from transplantation, can it be corrected so I can get a transplant?
- What is the recovery time?
- What are the side effects of the medicines?
- Will any of the anti-rejection medications interfere with any medicines I am currently taking?
- Will the anti-rejection drugs be changed if one is not working?
- How often do I need to see the transplant team?
- Do I need to see a nephrologist in addition to the transplant surgeon?
- If I live a distance from the transplant center and I have a medical problem, do I go to the closest hospital or go to the transplant center?
- What are the tests your transplant center requires and can they be done at my dialysis facility or nephrologists' office?

Some other areas that need to be explored are:

- **Finances and insurance:** Most transplant centers have a Financial Coordinator to assist patients to examine insurance coverage and how it will pay for the procedure, medication, and other elements of transplantation. In some transplant centers the Financial Coordinator may also be the Social Worker. Medicare D is complex and needs to be addressed before transplantation. The transplant and dialysis facility social worker can assist in investigating how Medicare D may pay toward immunosuppressant medication. Please refer to the Centers for Medicare & Medicaid Services booklet, **"Medicare Coverage of Kidney Dialysis and Kidney Transplant Services"** for a comprehensive explanation of the Medicare process. This booklet is available at http://www.medicare.gov/publications/pubs/pdf/esrdcoverage.pdf

- **Emotional and lifestyle issues:** Transplant centers have a Social Worker to help with emotional and lifestyle issues and concerns. The patient, family member or caregiver may have a work schedule, childcare, pets, or other family issues which need to be addressed before considering a transplant. Many patients do not realize that they will see a Social Worker who will assess and evaluate their needs and attempt to assist the patient to reach their needs before transplantation.

- **Transportation and lodging issues:** The transplant center will help with applications for assistance programs or resources. The resources may not be the same for all transplant centers. The dialysis facility Social Worker can also assist with any local resources, which may be available as well as possible coordination of services.

Transplantation takes a **commitment** from the patient to do their best to follow the doctor's orders, take the necessary medication (without skipping) and letting the doctor know of any issues that may arise. Having a strong support system is very helpful. If family involvement is present, they need to be aware of the patient's situation, needs, and responsibilities.

The *Southeastern Kidney Council Resource Directory* contains a comprehensive listing of transplant resources.

The Benefits of Volunteering

Let's face it. Most people on dialysis are not employed. Some individuals long to work again but have found managing a job as well as dialysis to be simply too difficult and exhausting. Others may voluntarily remove themselves from the grind of the workday world, if financially feasible, in order to spend more time with family or attend to health issues. Many others are in retirement. Regardless of which reason applies, everyone whose employment has ended due to age, disability, or incompatibility with medical treatment regimens may face similar effects: the loss of feeling useful, lowered self-esteem, having too much time on one's hands, having fewer social outlets, loss of self-confidence, and perhaps depression. If this describes you or someone you know, please consider the benefits of volunteering.

Volunteering is when you give your time to help another person, group, or cause. There is a long list of possible advantages to those who volunteer. Author Allan Luks explores some of them in his book, The Healing Power of Doing Good: The Health and Spiritual Benefits of Helping Others. Some of the advantages he lists are:

- A more optimistic and happier outlook on life
- A heightened sense of well-being
- An increase in energy
- A feeling of being healthy
- Decreased feelings of loneliness, depression, and helplessness
- A sense of connectedness with others
- A greater sense of calmness and relaxation
- An improvement in insomnia
- A stronger immune system
- A reduction in pain
- Speedier recovery from surgery

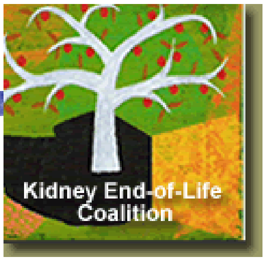
Volunteer activities also offer a meaningful way to interact in a world that may otherwise focus on the limits of people who are on dialysis instead of showcasing what they can do, not only for themselves, but also for others. Volunteering is a selfless way to "give back" and acknowledge one's own prosperities. It's a way to promote lifelong learning and also self-examination. Volunteering can add structure to one's daily life.   Lastly, in some cases it's possible for a volunteer experience to result in a paid position. Whatever your motives, consider volunteering for the potential benefits it holds for you.

Source: ESRD Network 15

Treatment Options: Making the Right Decision

When your kidneys fail, you need treatment to replace the work of your once healthy kidneys. If you choose to receive treatment, your choices are hemodialysis, peritoneal dialysis, or a kidney transplant. Each option has advantages and disadvantages. By learning about your choices, you can better decide what's best for you. Ongoing education regarding your options is vital. Increased knowledge can give you confidence and empowerment. No matter which treatment you choose, you'll need to make some changes in your life, including how you eat and plan your activities. With the help of your family, friends and health care team you can lead a very active and healthy life. For more information on treatment options and other related topics visit our website at www.esrdnetwork6.org.

Advanced Care Planning



Today's treatments for kidney failure allow you to participate in life and enjoy your family and friends. Dialysis is a life-saving treatment, but it is not a cure. Most people with kidney failure have other diseases or conditions that get worse over time. At some point, you could face failing health and – as all people do, regardless of their health – the end of life.

Looking ahead can be overwhelming and scary to think about. But it helps to take control of your care by telling your health care providers and your family about your wishes and the type of care you want as your disease progresses. This also will make it easier for them to make decisions for you if you become too sick to make them yourself.

Many people on dialysis say they feel better knowing that they talked with their family or social worker about their wishes for the future. They say that they:

- Feel a sense of control over their future
- Have peace of mind
- Know they have made sure that they will be taken care of with dignity, through pain relief and other chosen treatments
- Feel they will be less of a burden to their family, who will not have to make difficult decisions on their behalf

All of these decisions are called "advance care planning," which is simply planning for your care before you need it. To start, consider the following questions:

- How do you feel about your current health and life?
- What do you value about your health and life now?
- How important is it for you to be independent, able to recognize family and friends, able to talk and understand others, and able to live without pain?
- Are there any situations – such as permanent unconsciousness, severe dementia or stroke – in which you would not want to be kept alive with a breathing machine or a feeding tube, or other measures?
- Are there any situations in which you would want to stop dialysis?

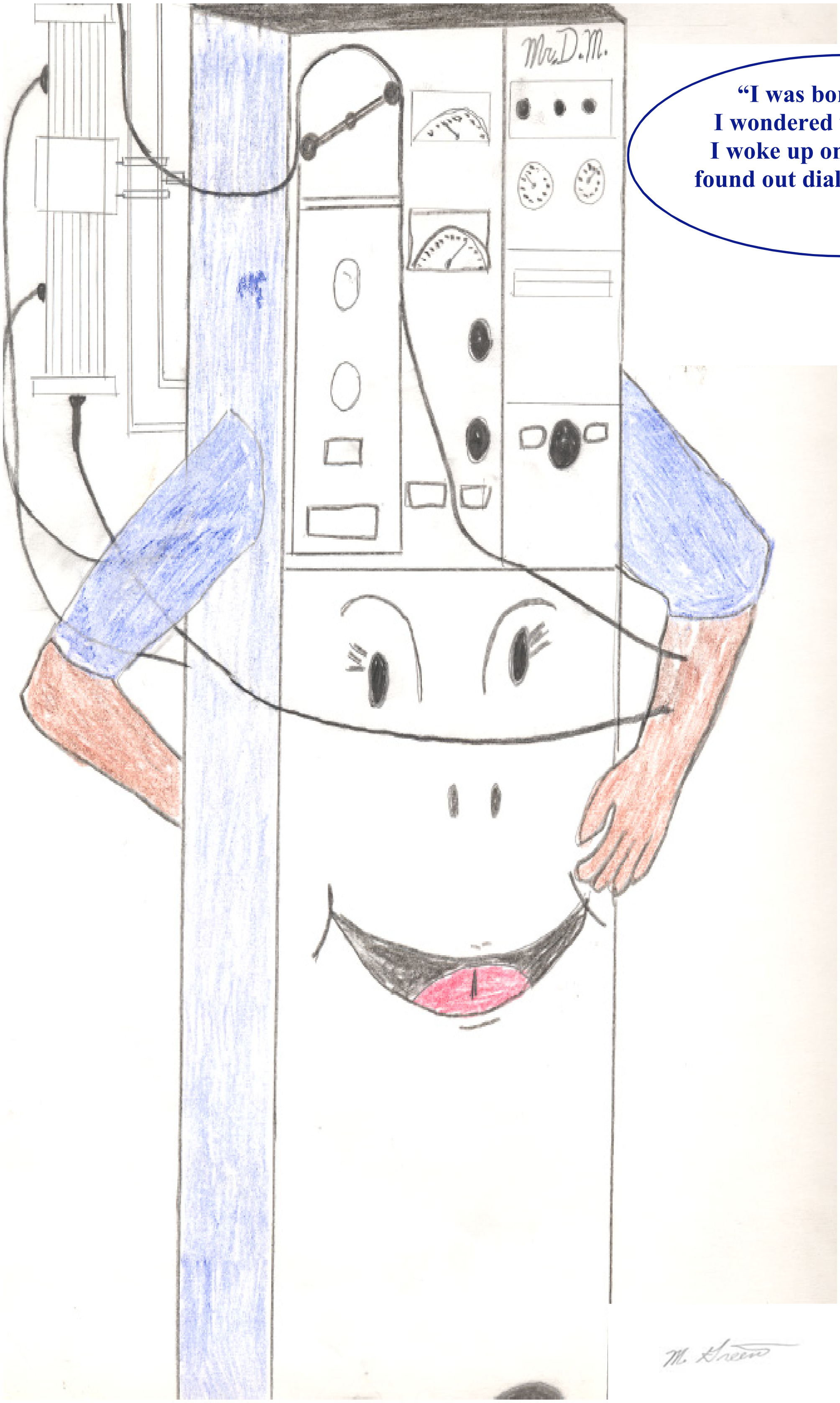
Your dialysis facility staff are ready to work with you on putting some of these decisions in writing so you can have peace of mind about your future. You can always change any of your decisions later; they are not set in stone. For more information or additional resources, visit Kidney End-of-Life Coalition's website at www.kidneyeol.org.

Source: "Advance Care Planning: For the Dialysis Patient and their Family," Mid-Atlantic Renal Coalition

Living with Kidney Failure Booklet

The Southeastern Kidney Council is pleased to announce that the 2005-2006 Consumer Committee has revised the *Living with Kidney Failure* booklet. The Consumer Committee originally created the booklet in 1988. This booklet contains valuable information and resources regarding chronic kidney disease, including treatment options, disaster preparedness, vascular access, and much more! You can download the booklet from the resources section of our website at www.esrdnetwork6.org/Resources.htm. If you do not have Internet access, see your facility social worker for assistance.

Quality Dialysis Gives Life!



"Quality Dialysis Gives Life" artwork submitted by Alphonso Green of Statesboro, Georgia.

News From the Georgia Association of Kidney Patients (GAKP)

As we stated in the last issue of *Renal Health News*, the main item on GAKP's agenda this year is working on state legislation on behalf of Georgia kidney patients. As promised, Senator Renee Unterman, a former nephrology nurse, reintroduced the dialysis technician certification bill (now SB 57). The bill is unchanged from last year. The bill will require dialysis technicians to pass a nationally recognized competency exam. As we write, the bill has passed out of the Senate and is headed for the House.

In other legislative news, Senator Don Thomas, a physician, introduced SB 45 that creates a kidney disease task force to study kidney disease. The task force is charged with making plans to educate professionals and the public about kidney disease and to make plans for early screening and diagnosis. The task force must complete its work by December 31, 2007 and will then cease to exist. A cross section of the renal community is represented on the task force including the Georgia Association of Kidney Patients.

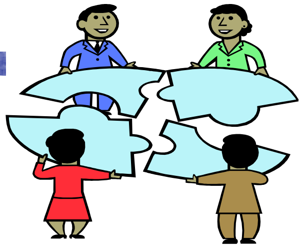
Senator Preston Smith from Rome, Georgia is preparing a Senate Resolution to honor GAKP board member David Shore who passed away on October 15, 2006 from complications related to a liver/kidney transplant. Before joining GAKP and working on legislative issues, David was a long-time advocate for the disabled. Senator Smith will present the resolution to David's mother on February 22, 2007 at the state capitol.

Finally, Senator Tommie Williams of Lyons, Georgia introduced Senate Resolution 94 that commended the Georgia Renal Coalition and recognized January 31, 2007 as "Georgia Dialysis Day." GAKP is a member of the Georgia Renal Coalition that is an affiliate of the National Kidney Disease Education Project.

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 themselves can best protect patients' interests. Our motto is "Putting Patients First Always." GAKP invites Georgia kidney patients to join in order to meet and learn from other patients and educational programs and to help us advocate for kidney patients. GAKP meets at Piedmont Hospital in Atlanta at 2:00 pm on the third Sunday of January and every other month thereafter. Family membership is $10.00 per year and may be paid to GAKP and sent to Boo Hall, Treasurer, 28 Velma Drive, Newnan, Georgia 30263, or you may contact Joel Kollin, president, at 770-392-7958 or jkollin@comcast.net. Our new website at www.gakp.org is currently under construction.

Article submitted by George Harper M.Ed, Ed.S, *Georgia Association of Kidney Patients* .

Georgia Patient Workshop



Mark Your Calendar: Thursday, May 17, 2007
The Southeastern Kidney Council and National Kidney Foundation of Georgia are hosting the Georgia Chronic Kidney Disease Patient Workshop, "Chronic Kidney Disease: Piecing it Together" on Thursday, May 17, 2007 at the Savannah International Trade & Convention Center in Savannah, Georgia. Topics to be discussed include Preparing for the Unexpected, Vascular Access, Vocational Rehabilitation, Transplantation and Intimacy. To register, please contact the National Kidney Foundation of Georgia at (770) 452-1539 or (800) 633-2339. Brochures will be mailed to dialysis facilities in March 2007.

Consumer Committee Elections

The Consumer Committee is one of several committees at the Southeastern Kidney Council in which patients serve as active members. End Stage Renal Disease patients are "consumers" of dialysis and transplant services, thus the name given to the committee. The purpose of this committee is to provide the Board of Directors and the Medical Review Board with consumer views and concerns regarding all areas of the organization, quality of care and issues related to patient grievances and patient rights. The Consumer Committee develops patient education resources and contributes to the *Renal Health News* patient newsletter.

The Southeastern Kidney Council is now accepting nominations for new members to join the Consumer Committee. Members serve two-year terms for up to three consecutive terms. The Committee will consist of a maximum of 17 members including the Chairperson. If you, or someone you know, are interested in serving on the Consumer Committee, please return the nomination form as instructed.

We are seeking nominations for all positions from the following disciplines/backgrounds:

9 Consumers

- 3 Representatives from North Carolina
  - Hemodialysis
  - Peritoneal or Home Hemodialysis
  - Transplant
- 3 Representatives from South Carolina
  - Hemodialysis
  - Peritoneal or Home Hemodialysis
  - Transplant
- 3 Representatives from Georgia
  - Hemodialysis
  - Peritoneal or Home Hemodialysis
  - Transplant

3 Nephrology Professionals (Social Worker, Dietitian, Physician, Nurse, and/or Patient Care Technician)
5 At-Large Positions (Nephrology professionals, patients, or family members)

Before you nominate someone, please be certain they are willing to serve and are able to perform the following duties as listed in the job description. You may self-nominate.

Consumer Committee Job Description

- Convey the opinion of consumer views as related to all relevant topics.
- Assist in the development of consumer driven patient educational materials as needs are identified.
- Assist in developing and implementing the Network's complaint and grievance procedure.
- Attend meetings and show commitment to Southeastern Kidney Council activities.
- Be well-informed on issues and agenda items in advance of meetings.
- Contribute skills, knowledge and experience when appropriate.
- Represent the Southeastern Kidney Council to the public and private industry.
- Be educated about the requirements of the contract with the Centers for Medicare & Medicaid Services, and the Network's Statement of Work.

Southeastern Kidney Council
Nomination Form
Consumer Committee

Your Name: ____ Phone: ______________________________

E-mail: ____

Signature: ____

About the Nominee

Name: ____

Current Job Position (for allied health professionals): __________________________________

Home/Facility/Practice Name: ____

Home/Facility/Practice Mailing Address: ____

____

Phone: ____

Fax: _______________________________ E-Mail: ____________________________

Current Modality: ____

Years at this Modality: _______

Other Renal Organization Affiliation(s): ____

Previous Southeastern Kidney Council Board/Committee Experience: ____________________

____

____

Short background/biographical information: ____

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____

What else should voters know about the candidate? ______________________________

____

____

To Be Completed By The Nominee

What goals and objectives would you like to see the Southeastern Kidney Council's Consumer Committee to achieve in the next two years? As a member of the Committee how would you assist in accomplishing those goals? Are there any specific areas of care that you would like to see the Board develop evaluation programs for or monitor?

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I have read the attached Consumer Committee objectives and obligations and agree to be nominated to the Consumer Committee.

Signature: ____

Nominations close April 30, 2007 at 4:00 pm

Consumer Committee Members will be elected at the next Consumer Committee meeting on July 19, 2007. Elected members would be expected to attend the following meeting in January 2008.

Return the completed Nomination form(s) to:

Amy Byrd
Southeastern Kidney Council
1000 St. Albans Drive, Suite 270
Raleigh, NC 27609
Fax: (919) 855-0753

If you have any questions, contact Amy Byrd or Tiffany Washington, at (919) 855-0882.
Nominations close April 30, 2007 at 4 pm.

Southeastern
Network 6 Kidney Council, Inc.

1000 St. Albans Drive, Suite 270
Raleigh, NC 27609
Phone: (919) 855-0882
Fax: (919) 855-0753
Patients Only: (800) 524-7139
Executive Director: Jenna Krisher
Editor: Amy Byrd, Education Coordinator

Consumer Committee Members:
Chair: Noreen Rogers
Bonita Balkcom Guilford
Carl Brooks
Jennifer Graves
George Harper M.Ed., Ed.S
John Haynes CPA
W. Merrill Hicks MD
Jim Humphrey
Pearl Magovern MSW
Mary Claire Montilus
John H. Robinson
Richard Rogers
Elizabeth Simmons
Thomas Taylor
Willoughby Taylor
Wayne Welborn

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

This is YOUR newsletter! Please send us your ideas, stories, articles, and recipes. We'd love to hear from you .

Please mail them to:
Southeastern Kidney Council
Attention: Amy Byrd
1000 St. Albans Drive
Suite 270
Raleigh, NC 27609
Educoordinator@nw6.esrd.net

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

1-800-524-7139

If you have questions or concerns, please call.

Have you Moved?

Remember, 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.

Check out our website:
www.esrdnetwork6.org

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