

Southeastern Kidney Council Presents: **Kidney Spotlight**

A Newsletter for Patients,
Families and Dialysis Staff

April 2011

Role of the Southeastern Kidney Council

Who is the Southeastern Kidney Council?

- Southeastern Kidney Council is a non-profit company that holds the contract for ESRD Network 6 covering North Carolina, South Carolina, and Georgia
- Network 6 is one of 18 ESRD Networks contracted by Centers for Medicare & Medicaid Services for quality oversight of dialysis facilities
- Network 6 is the largest Network in the United States with more than 38,000 dialysis patients and 570+ dialysis and transplant facilities

What Can We Do for You?

- Provide Technical Assistance to facilities to help improve Quality
- Assist facilities in formulating Quality Improvement (QI) Plans
- Assist facilities and patients in resolving Complaints and Grievances
- Provide patient and facility education

How Can You Get Involved?

- Run for the Network 6 Board of Directors, Medical Review Board, or Consumer Committee (Job descriptions and nomination forms are included in this newsletter)
 - Make recommendations regarding patient health care messages, materials and activities
 - Provide feedback on effectiveness of Southeastern Kidney Council activities
- Join a support group or organize a patient council in the dialysis clinic

In this Newsletter:

- Role of Southeastern Kidney Council
- Nomination for SKC Committees
- Treatment Options
- Importance of a Positive Attitude
- Emergency Preparedness
- 5-Diamond Patient Safety Program
- Chuck Brown Memorial Award
- Patient Ambassador Program

Checklist for SKC Committees



Board of Directors (BOD): To develop policies, procedures and regulations for the operation of the Southeastern Kidney Council; to monitor finances, programs and performance of the organization

Consumer Committee (CC): To provide the Board of Directors and 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. Develop educational materials for Network 6 consumers.

Medical Review Board (MRB): To develop programs for the evaluation of the quality and appropriateness of care delivered to ESRD patients in the Network 6 area.

Term: Members serve for two years with a maximum of three consecutive terms. After serving a third consecutive term, member must rotate off the committee for at least one year before being eligible for re-election.

Expected In-Person Meeting Attendance (May also have conference calls):

- Medical Review Board—3 times per year
- Consumer Committee—2 times per year
- Board of Directors—2 times per year

Specific Duties:

- 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
- Listen respectfully to other points of view
- Represent the Southeastern Kidney Council positively to the public and private industry.
- Educate yourself about the requirements of the contract with the Centers for Medicare & Medicaid Services
- Refrain from participating in any review of services of any ESRD facility in which you have a financial interest (direct or indirect) or any professional involvement

Who Can be a Member:

- Consumers (ESRD Patients or Family Members)
- Dietitians
- Nurses
- Renal Physicians (Nephrologists and/or Surgeons)
- Social Workers
- Patient Care Technicians
- Facility Administrators

Return the nomination form on the following page by May 5, 2011
Amy Williams, 1000 St. Albans Drive, Suite 270, Raleigh, NC 27609
Fax : 919-855-0753 E-mail: info@nw6.esrd.net

SKC Committee Nomination Form

Nominator's Name: _____ Phone: _____

(you can self-nominate)

Nominee's Signature: _____

Nominee's information:

Committee (Select One):

- Board of Directors
- Medical Review Board
- Consumer Committee

Name: _____

Dialysis Facility (Where you work or dialyze) _____

Preferred Mailing Address: _____

Phone: _____

Fax: _____ E-Mail: _____

Education/Training: _____

Current Position:

- Consumer (ESRD Patient or Family Member)
- Dietitian
- Nurse
- Renal Physician (Nephrologist and/or Surgeon)
- Social Worker
- Patient Care Technician
- Facility Administrator

Years Working in Nephrology: _____ Years on ESRD (Patients): _____

Other Renal Org. Affiliation(s): _____

Primary skill that Nominee would offer to the SKC :

What goals and objectives would you like to see the Southeastern Kidney Council's committees achieve in the next two years? As a member, how would you assist in accomplishing those goals? (Use additional paper if needed):

Alternatives to In-Center Hemodialysis

Home Hemodialysis

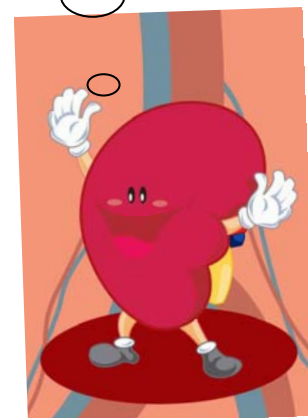
- Types of Home Hemodialysis
 - Conventional home hemodialysis (4 hour treatments, 3 times a week)
 - Daily home hemodialysis (2-3 hour treatments, 5-6 days a week)
 - Nocturnal home hemodialysis (Nightly 6-8 hour treatments, 3+ days a week)
- Flexible schedule allows you to work, volunteer, attend school or other community activities
- Less restrictive diet and fluid intake
- No weekly travel to facility required
- More control of your dialysis

Peritoneal Dialysis

- Types of Peritoneal Dialysis
 - Continuous ambulatory peritoneal dialysis (CAPD)
 - Continuous cycling peritoneal dialysis (CCPD)
- Less restrictive diet and fluid intake
- No needles required for treatment
- Flexible schedule
- Need clean, dry area to store supplies
- Need clean environment to avoid infection

Transplantation

- 3 types of kidney transplant donors:
 - Living relative
 - Living non-relative
 - Deceased (cadaver)
- No Dietary Restrictions
- Return to a more normal lifestyle
- Increased life expectancy
- Need to take medications to prevent possible side effects
- Talk to transplant financial coordinator to make a financial plan



Kidney Transplant

Georgia Transplant Centers:

- Egleston Children's Transplant: 800-605-6175 or 404-785-1405
- Emory University Transplant: 877-509-9877 or 404-727-0717
- MCG Health Transplant: 800-736-2273 or 706-721-2888
- Piedmont Hospital Transplant: 888-605-5888 or 404-605-4600

North Carolina Transplant Centers:

- Carolinas Medical Transplant: 800-562-5752 or 704-355-6649
- Duke University Transplant: 919-684-5859
- Pitt County Memorial Hospital Transplant: 252-744-2620
- UNC Hospital Transplant: 888-263-5293 or 919-966-9950
- WFU Baptist Medical Center Transplant: 336-716-0548

South Carolina Transplant Centers:

- Medical University of SC Transplant: 800-277-8687 or 843-876-1580

Frequently Asked Questions:

How much does it cost?

- Varies due to your insurance coverage
- Medication costs can be high
- May involve need for fundraising
- Your transplant center has dedicated staff to ensure your understanding of your financial responsibilities

What do I have to do to get a kidney transplant?

- Have your doctor or dialysis center refer you to a kidney transplant program
- You will be evaluated medically and psychosocially
- Your name will be placed on the national wait list if approved for transplant.
- Living donors will be evaluated

What happens after my transplant?

- You will be followed by your transplant center closely during the first several weeks after your transplant
- You may then be followed by your local nephrologist
- You will take medications to keep your body from rejecting your new organ for the rest of your life

Questions to ask transplant center

- What are my risks and benefits of transplant?
- What are your success rates?
- How long will I have to wait?
- What does my insurance cover?
- What are my financial responsibilities?

TRANSPLANT RESOURCES

- Southeastern Kidney Council: 800-524-7139 or www.myskc.org
- American Association of Kidney Patients: 800-749-2257 or www.aakp.org
- Georgia Transplant Foundation: 770-457-3796 or www.gatransplant.org
- National Kidney Foundation: 800-622-9010 or www.kidney.org
- National Transplant Assistance Fund: 800-642-8399 or www.transplantfund.org
- United Network of Organ Sharing (UNOS): 888-894-6361 or www.transplantliving.org

The Importance of a Positive Attitude

“You have lost your kidney function and must start dialysis immediately in order to sustain your life.” These are the life changing words that most of us that are faced with dialysis every other day have heard. When my Nephrologist informed me that the Systemic Lupus had severely damaged my kidneys and that I had failed the chemotherapy treatment that was supposed to save my kidney function, I was devastated. How would dialysis affect the quality of my life? How would I, a 26 year old woman, still be able to live and do the things that young women like to do? What would this new change mean for my family?

In the days and weeks following my initial diagnosis of End Stage Renal Disease, I was overwhelmed with all the new information, frustrated that I would have to spend ten hours of my life each week sitting in a clinic, held hostage by a machine that beeped at the slightest movement I made, and sad at the possible implications of what dialysis would mean in my life. Was I going to let the loss of my kidneys dictate what I could and could not do with my life? Would I let dialysis define who I was or what I could become? How could I turn this seemingly negative situation into a positive, new addition in my life not only for myself but for others around me? These were the tough questions I was now faced with everyday.

While I allowed myself to be angry, confused, and frustrated, I refused to let these emotions consume me. I learned that my happiness was up to me. I realized that I could become bitter and resentful at all life was throwing my way or I could accept what life was giving me and make the absolute most with all that I had.

Several weeks ago I had a routine visit with my rheumatologist. As she glanced at my lab reports, she seemed baffled. After about twenty seconds she commented, “I have never seen anyone on dialysis with such beautiful labs. I can’t explain it.” After several minutes of us chatting, she later said, “I wouldn’t be at all surprised if the positive attitude you have maintained is contributing to your good health.”

Continued on next page

I urge you to never underestimate the power and importance of keeping a positive attitude. Research has shown a critical correlation between positive attitudes and the healing process. I am a living testament to this connection. Two months after being hospitalized for four weeks, suffering a heart attack, and going into kidney failure, I enrolled in a Master of Music in Flute Performance program at East Carolina University. I managed to complete this demanding course of study in two years, attending classes primarily on Mondays, Wednesdays, and Fridays (non-dialysis days). I have traveled all across the country, performing in master classes with world-renowned flutists. In May 2010, I graduated with a Master of Music degree in Flute Performance. I will pursue a Doctorate of Musical Arts degree at one of the nation's top music conservatories in the fall of 2011. I am currently on the national renal transplant donation list and hope to receive a kidney transplant soon.

I share my story with you, dear reader, because I have learned that having a positive attitude in the midst of a storm reaps great benefits for your mental and physical health and your quality of life. Ask yourself what you would do if dialysis were not a part of your life. Then, go for it! Live! Carpe Diem! I am positive that you will find that you can do just about anything you want to do. Remember, dialysis is a part of your life. It does not define your life. I will leave you with a quote that has served as a source of inspiration and hope for me on my life voyage: "Life isn't about waiting for the storm to pass. It's about learning to dance in the rain."

Tunisia L. Bullock, Kidney Dialysis Patient since June 2008

Send us your Story, Poem, Artwork, or Recipe to include in our future newsletters!

**Southeastern Kidney Council
Amy Williams
1000 St. Albans Drive Suite 270
Raleigh, NC 27609**

Developing a Plan for Disasters

The 2011 Hurricane Season officially starts on June 1, 2011 and ends on November 30, 2011. However, disasters can happen at anytime—snow, flood, tornado, etc. In addition, there are man-made disasters like terrorism or chemical spills.

Dialysis facilities are responsible for developing plans to prepare for and respond to disasters and emergencies. These plans must be properly established and shared with all staff and patients. It is extremely important that dialysis patients, develop your own personal plan, as well.

Tips to Developing Your Plan:

- Plan for back-up transportation to dialysis
- Learn which evacuation zone your home is in
- Learn your dialysis facility's emergency policies
- Update your contact information at the facility so they can call you if the schedule changes
- Gather emergency supplies, medicines & personal papers and place in a secure container
- Get a copy of the emergency diet for dialysis patients
- Get a list of dialysis facilities and hospitals in the area
- Ask your social worker about "special shelters"
- Write down toll-free numbers to call for dialysis after the event (if your facility is closed)
- Listen to local TV and radio for "dialysis updates"
- Follow your physician's advice regarding diet & fluid intake during a disaster, when possible
- Follow the same frequency for dialysis services when possible. Services may be harder to find so don't wait too long to start looking. Following the emergency diet can help if you can't get to services for a day or two.
- PD patients should have enough supplies for 5-7 days
- Transplant patients should have enough medicine for two weeks

Basic emergency items:

- Flashlight and Batteries
- First Aid Kit
- Medicines
- Candles and matches
- Plastic jugs for water
- Important papers

Resources Available:

- *Emergency Preparedness Guide: A Resource for ESRD Patients*—Contact Southeastern Kidney Council for your copy or download from www.myskc.org
- Kidney Community Emergency Response Coalition—<http://www.kcercoalition.com>
- Dialysis Facility Compare—www.medicare.gov/dialysis

Contact the Southeastern Kidney Council at (800) 524-7139 if you need assistance in developing your plan or have any questions regarding emergency preparedness. In addition, the Southeastern Kidney Council is available to assist patients in the event of



5-Diamond Patient Safety Program

The Southeastern Kidney Council launched the *5-Diamond Patient Safety Program* to assist dialysis facilities with the improvement of both staff and patient awareness of specific patient safety areas. Objectives include:

- To build a patient safety culture in every dialysis unit
- To promote patient safety values
- To create an awareness of patient safety issues
- To help dialysis units learn more about specific areas of patient safety

The *5-Diamond Patient Safety Program* consists of educational modules, which include the tools and resources necessary for implementation of each patient safety concept. For each module successfully completed the facility is awarded a “diamond” culminating in special recognition for the 5-Diamond facilities. Recognition rewards are posted on our website www.myskc.org and include:

5-Diamond

- DaVita Atlanta Dialysis
- Dillon Dialysis
- DCI Saluda
- FMC Marshlands Dialysis
- Harbin Clinic Dialysis
- Harbin Clinic Summerville Dialysis
- Harbin Clinic Cedartown Dialysis
- High Point Regional Health System
- Low Country Dialysis
- RAI Care Centers North Charleston
- Renal Care Partners of Dunwoody
- Wake Forest Dialysis Center

4-Diamond

- Davie Kidney Center
- FMC Houston County
- US Renal Care Hawkinsville

3-Diamond

- DaVita Central Bamberg
- Elkin Dialysis Center
- High Point Kidney Center
- King Dialysis Center
- Mount Airy Dialysis
- Northside Dialysis Center
- Piedmont Dialysis Center (Winston-Salem, NC)
- Salem Kidney Center
- Statesville Dialysis Center Inc.
- Thomasville Dialysis Center
- Triad Dialysis Center

2-Diamond

- DSI Covington Renal Center
- FMC Cheraw Dialysis
- FMC Clinton Dialysis
- Lake Norman Dialysis Center
- Lexington Dialysis Center
- Miller Street Dialysis
- West Iredell Dialysis Center
- Yadkin Dialysis Center

1-Diamond

- Athens Kidney Center
- Commerce Kidney Center
- Loganville Dialysis Center
- Spring Hope Dialysis
- West Georgia Dialysis
- Wilkes Regional Dialysis Center

Please visit us online at www.myskc.org for more information or to join the program. This program was developed by the Mid-Atlantic Renal Coalition and the ESRD Network of New England.

The Chuck Brown Memorial Award

NOMINATION FORM

Deadline: May 31, 2011

In 2003, the Southeastern Kidney Council created the Chuck Brown Memorial Award to honor the memory of a beloved member of our renal community. The purpose of the award is to recognize an individual(s) or organization that exemplifies the mission and goals of the Southeastern Kidney Council.

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*. The Network goals include improving dialysis quality and safety, improving independence by promoting home dialysis options and in-center self-care, resolving patient complaints and grievances, improving provider collaboration and improving data collection to measure care and outcomes.

Please write **CLEARLY, NEATLY and LEGIBLY**. Please feel free to type the answers in a Word document and send to us. The Consumer Committee members need be able to clearly read the form in order to best assess the nomination. Please be very detailed and thorough in the descriptions.

The nominee's name: _____ Telephone number: (____) _____

Nominee's email: _____

Dialysis Facility (if applicable): _____

Your name: _____ Telephone number: (____) _____

Your email: _____

Please complete the following:

1. What population does this person/organization impact?

- One patient
- A group of patients
- One state in Network 6 (Georgia, North Carolina, South Carolina)
- Multiple States in Network 6 (Georgia, North Carolina, South Carolina)
- Network 6 and beyond (national level)

2. Which of the Network goal(s) does this person/organization impact and how?

- Improves the quality and/or safety of dialysis related services
- Improves the independence, quality of life, and rehabilitation (to the extent possible)
 - Through transplantation
 - Use of self modalities (PD, home hemodialysis)
 - In center self care
 - As medically appropriate, through the end of life
- Improves patient perception of care and experience of care
- Resolves patient complaints and grievances
- Improves collaboration between patient and providers to ensure achievement of patient goals
- Improves the collection, reliability, timeliness and use of data to measure processes of care and outcomes
- Maintains patient registry and supports the ESRD network program

Examples of how this person/organization reflects Network 6 goals
(Give detailed description for each goal selected) (Use additional paper if needed):

3. Which area(s) of care are impacted by this person/organization? (Provide details of HOW they impact the following)

Vascular Access:

Rehabilitation:

Advocacy:

Patient Education:

Quality of Life:

Disaster/Emergency Preparedness:

Other areas

4. How does this person/organization improve the lives of those with or at risk for End Stage Renal Disease? (Use additional paper if needed)

Mail or fax nomination form by May 31, 2011 to:

**Southeastern Kidney Council
Attn: Alesha Perkins
1000 St. Albans Drive, Suite 270
Raleigh, NC 27609
919-855-0882, ext. 38
Fax: 919-855-0753**

Patient Ambassador Program

The Southeastern Kidney Council (SKC) initiated a pilot patient ambassador program in December 2010 to facilities in the Raleigh/Durham, NC area. The program's purpose is to identify and train local ambassadors who will receive SKC information and will communicate feedback from patients and facility staff to SKC to assist in developing educational/outreach material.

Ambassadors Duties:

- Distribute educational material from Southeastern Kidney Council
- Meet with patients to discuss questions, challenges, and concerns related to their adjustment to dialysis
- Work with the care team to promote patient participation in quality improvement
- Promote patient participation in various surveys regarding ESRD
- Participate in monthly conference calls with SKC staff and Consumer Committee

Ambassadors do not distribute medical advice or function as a contact person for complaints and grievances.

To coordinate with the 2011 Patient and Family Educational Calendar distributed by SKC in December 2010, Ambassadors focused the month of March on Vascular Access. Ambassadors developed a bulletin board focusing on the importance of vascular access as well as promoting the Ambassador project. The bulletin boards were judged by the 2010 Consumer Committee. The winner of the vascular access bulletin board is Mr. Wayne Satterfield from Johnston Dialysis in Smithfield, North Carolina. Pictured below is Mr. Satterfield along with his Social Worker, Ms. Christy Nance MSW.

