

Get Involved In Your Kidney Community!

A Patient & Dialysis
Staff Guide to
Volunteerism

Role of the Southeastern Kidney Council

Who is the Southeastern Kidney Council?

- Southeastern Kidney Council is our incorporated name, and we hold the contract for ESRD Network 6
- Network 6 is one of 18 ESRD Networks contracted by Centers for Medicare & Medicaid Services for quality oversight of dialysis facilities in North Carolina, South Carolina, and Georgia
- Network 6 is the largest Network in the United States with more than 34,000 dialysis patients and 560+ 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) Initiatives
- 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 Committees (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 the Network's activities
- Join a support group or organize a patient council in the dialysis clinic
 - Share knowledge and experience to increase the likelihood that all patients will have the best quality of care
 - Feel a sense of caring and understanding

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 of the organization, its programs and performance.

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.

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

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 Meeting Attendance:

- 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 when appropriate
- Listen respectfully to other points of view
- Represent the Southeastern Kidney Council 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)
- Dietitians
- Nurses
- Renal Physicians (Nephrologists and/or Surgeons)
- Social Workers
- Patient Care Technicians

**Return the nomination form on the following page to
Amy Williams, 1000 St. Albans Drive, Suite 270, Raleigh, NC 27609
or fax to 919-855-0753 by April 30, 2010**

Dialysis and Transplant Support Groups in Your Area

Asheville, North Carolina

When: First Thursday of every month from 5:00 to 6:00 pm

Where: Asheville Kidney Center, 1600 Centrepark Drive, Asheville, NC 28805

Contact: Shaun Boyd LCSW, (828) 251-1224

Who should attend? Pre-dialysis patients, dialysis patients, transplant candidates, transplant recipients and caregivers

Charlotte, North Carolina

When: Second Tuesday of every month from 6:30 to 8:30 pm

Where: Carolinas Medical Center, 1000 Blythe Blvd 3rd floor, Dining Room #2, Charlotte, NC 28232

Contact: Sammy Bailey, (704) 503-6900, ext. 213

Who should attend? Pre-dialysis patients, dialysis patients, transplant candidates, transplant recipients and caregivers

Durham, North Carolina

When: Second Tuesday of every month from 6:30 to 8:00 pm

Where: Duke University Medical Center Clinics, Room 1993 (Across from Clinic 1C) 200 Trent Drive, Durham, NC 27710

Contact: Kate Artin, (919) 681-1503

Who should attend? Transplant candidates, recipients, and caregivers

Call from home for FREE: (866) 579-8110, code 754116

Durham, North Carolina

When: Tuesdays from 1:00 pm - 2:00 pm

Where: Duke University Hospital, Room 4275, 2301 Erwin Road, Durham, NC 27710

Contact: Kate Artin, (919) 681-1503 or Jessica Farrell, (919) 681-5891

Who should attend? Caregivers for solid organ transplant candidates or recipients

Raleigh, North Carolina

When: First Wednesday of each month, 3:30 pm

Where: FMC Eastern Wake, 670 Granite Vista Drive, Rolesville, NC 27571

Contact: Bob Santasiero, (919) 870-1153

Who should attend? Pre-dialysis patients, dialysis patients, and caregivers

This newsletter was developed by the Southeastern Kidney Council under contract HHSM 500-2006-NW006C with the Centers for Medicare & Medicaid Services.

We need to hear from YOU! If you have questions, concerns, advice or would like to submit an article, poem, or artwork for our next newsletter, contact us at 1-800-524-7139 or email us at info@nw6.esrd.net. We are here to assist YOU!

Dialysis and Transplant Support Groups in Your Area

Atlanta, Georgia

When: Second Sunday of January, April, July and October at 2:00 pm

Where: Piedmont Hospital, 2004 building, 1968 Peachtree Rd NW, Atlanta, GA 30309

Contact: Deborah Moye, (404) 241-8955

Who should attend? Pre-dialysis patients, dialysis patients, transplant candidates, transplant recipients and caregivers

Douglasville, Georgia

When: First Monday of every month at 7:00 pm

Where: Douglasville Medical Building, Community Room, 8820 Hospital Drive, Douglasville, GA 30134

Contact: Donna Schwedt, (770) 505-3503

Who should attend? Transplant candidates, recipients, and caregivers

Griffin, Georgia

When: Second Tuesday of every month at 6:00 pm (March—October)

Where: Spaulding Regional, Women's Center Classroom, 601 South 8th Street, Griffin, GA 30224

Contact: Kim Wooster, (770) 229-9347

Who should attend? Pre-dialysis patients, dialysis patients, transplant candidates, transplant recipients and caregivers

Savannah, Georgia

When: Second Tuesday of every month at 5:00 pm

Where: Memorial University Hospital, Hoskins Building, Classroom 1, 4700 Waters Avenue, Savannah, GA 31404

Contact: Ann Hartfield, (404) 357-8631

Who should attend? Transplant candidates, recipients, and caregivers

Dialysis and Transplant Support Groups From Your HOME!

Renal Support Network : www.kidneyspace.com

HOPEline: (800) 579-1970. Monday through Friday, 10 AM to 8 PM (Pacific Time). All operators are kidney disease patients.

Daily Strength: www.dailystrength.org/c/Dialysis/support-group

MD Junction: www.mdjunction.com/dialysis

Patient's Perspective: Support Groups

Why have I attended four different support groups over the past forty years?

- ***I get help when I need it.*** People may help you even if you don't ask, and there is no requirement to share. You can just sit and listen. If you attend, someone will help you in some way.
- ***I look beyond myself to help others.*** This heavenly feeling comes across you when you have helped another without benefit to yourself.
- ***Education.*** Nurses, doctors, dieticians, psychologists, social workers, and technicians attend. We learn from them and they learn from us.
- ***Group dynamics are very helpful.*** Problems usually look smaller after saying them out loud. Groups help us gain needed perspective.
- ***Grief can be lessened.*** Losing one's kidneys, lifestyle, or feeling bad physically, or as a burden to others is difficult but normal. Support groups give you another lifeline besides your own coping skills.



So here is unasked for advice, from someone who has been end stage twenty years:

Get over the shyness of meeting so many people or talking in a group

Realize how much you will learn that may help you live

Share as much as you can with comfort - you will help another person

Trust that the time you spend in the group will enhance your life

There is much more to tell, but find out for yourself in your unit or nearby units. If you cannot find one, consider starting one. It's easy. Ask your doctor or social worker about the possibility. Our Social Worker, Shaun Boyd MSW kindly offered assistance.

You are not whining when you attend a group, you are simply being human and seeking help. I am proud of being able to do that.

Georgia Rohan, Asheville, North Carolina

The Caregiver's Heart—True Love

You nurture your true love, and
 You make him strong when he is weak.
 You will not let him go astray, you will watch over him.
 You will give him hope and courage.
 You will not let him stumble; you will pick him up.
 The Bible says that two is better than one.
 You will feel his pain, you will see beyond the surface,
 And you will know his thoughts and his limitations.

True love comes from the inside – that is what causes
 healing. It does not come from obligation, it is a matter
 of service from the heart.

You have the heart of Jesus to give the undying love
 which reaches into their mind, body and soul which is
 their spirit – man.
 The Bible says that love covers a multitude of things.

~~~~~ From one true Caregiver to another ~~~~~  
 Ella G. Long, Spartanburg, South Carolina

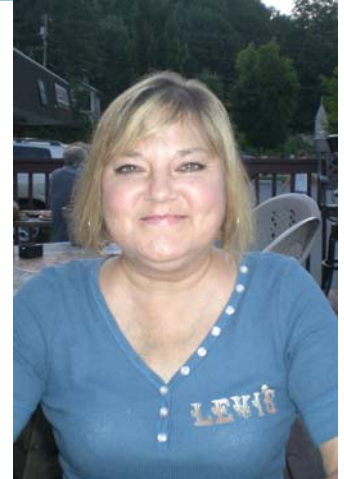
## My Soul Is A Watered Garden

My Soul is a Watered Garden—Flourishing for eternal life.  
 The everlasting love God gave me  
 brakes the tide of pain and strife.  
 My soul is a flower that's blooming  
 For the joy, praise and honor He gives.  
 My strength and hopes are budding  
 Within my eternal spirit that lives.  
 My fountain of tears are flowing  
 As they wash my own soul.  
 The garden of life within me is strengthened in the  
 Victory of salvation I hold.  
 My soul is singing with gladness  
 As He washes it with care.  
 As he gives me refuge from the storm I'll have no doubt of fear.  
 For as he waters my soul as His garden and tenderly watches over me  
 An everlasting peace within and a mansion externally.

Margie Gragg Matheson, Boone, North Carolina

## Patient's Perspective: Starting a Support Group

I am a dialysis patient and support group leader from Griffin, GA and I was diagnosed with End Stage Renal Disease (ESRD) in 1994. I had always been healthy and did not have a history of diabetes or high blood pressure so the diagnosis was very unexpected for my husband and I. We were living in Florida at the time and we decided it would be best to move back to Georgia, my home state, to be closer to family members who could help with my care until I got stronger. I was referred to a wonderful nephrologist in Atlanta who explained that I would need to go on dialysis since my kidneys were failing. Once I started dialyzing I began to feel much better because it removed the toxins and fluid that had built up in my body. Instead of sitting around waiting for treatment times, I decided to go back to school and get a degree at the local technical college. I would take a couple of classes at a time so it took a little longer but it was a great feeling of accomplishment especially since I had a chronic illness. I eventually got a part-time job at the college and was often asked to speak to the medical classes about kidney disease. That is when I gained a passion for sharing my knowledge and experience with the community so I began to look into starting a support group. I found out that the local hospital furnished rooms for support groups as part of their community programs and they made it easy to get started. The support group is called, Living with Kidney Disease, and I hold it the second Tuesday of every month. They advertise the support group in their quarterly newsletter and on their website. Then I contacted the National Kidney Foundation, Southeastern Kidney Council and several other organizations to get informational materials to hand out at meetings. They sent booklets on all the different dialysis options, diet plans, how to read labels, just a wealth of information and I am so glad to be able to share these with people who have just been diagnosed with ESRD or are already on dialysis. There are many options to keep ESRD patients alive and able to lead full lives. Sometimes I may have a small group, sometimes a big group but even if just one person comes and they needed that support it makes it all worthwhile. My main reason for doing this is to let people know that there is life after being diagnosed with kidney disease and that you need to be pro-active in your own care and always plan for tomorrow.



Kim Wooster, Griffin, Georgia

## Exploration

Dreams have teased her awake  
 Creating a space she cannot define  
 Flooding her with love and curiosity  
 There are no boundaries, no borders  
 Suffering is not on the edge anymore  
 It has invaded her life  
 Stolen her bliss  
 Yet brought it into focus  
 Living because of a machine  
 Her own organs have failed to sustain her  
 Yet the unturned stones of her life  
 Sparkle like gems of unknown origin  
 She struggles to pick them up  
 To turn them into something real  
 While her mind soars and spirals  
 Toward the inevitable  
 Finality is lurking around the corner  
 Trying to catch her unaware  
 She keeps dancing ahead of it  
 Wringing more out of every moment  
 Than anyone has a right to claim  
 Truth is something she owns  
 Despite its belonging to everyone in equal measure  
 Exploration is the game and also the prize  
 Her eyes see the goal  
 And her spirit respects no boundaries  
 She seeks a wedge of freedom  
 In a tethered, tired world.

Georgia Rohan, Asheville, North Carolina



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

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

## Though The Rain May Fall, The Sun Will Forever Shine

Sometimes in life, we may feel like we are in a down pour,  
 Drenched in buckets of rain water. Things might not be  
 Pleasant in our lives all the time, but in the down  
 pours of life, you can be sure the sun will shine, and  
 life will be a whole lot better. When the rain begins to fall,  
 Then fall on your knees and look to the sun, because it will  
 surely shine today, tomorrow, and forever.

© 1997. Cassandra Lee Barr, Hemingway, South Carolina

# The Chuck Brown Memorial Award

## NOMINATION FORM

**Deadline: April 30, 2010**

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?

- Improve the quality and/or safety of dialysis related services
- Improve 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
- Improve patient perception of care and experience of care
- Resolve 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

*Continued on next page*

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)

Adequacy of dialysis:

---

---

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 April 30, 2010 to:**

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

## Life Options

Life Options is a program of research, research-based education, and outreach founded in 1993 to help people live long and live well with kidney disease. A national panel of doctors, researchers, patients, nurses, social workers, dietitians, and ESRD Network directors reviews all Life Options materials and helps guide research. Through initiatives for patients and professionals, Life Options facilitates and supports efforts targeted in the areas of:

- Improving health-related quality of life
- Increasing survival and wellness
- Enhancing knowledge about how to live with kidney disease and treatment
- Increasing capacity for productive living
- Encouraging cost-effective care

Life Options booklets for patients and professionals published online include

- *Encouragement: Bridging the Barriers (For Patients and Their Families)*
- *Exercise: A Guide for People on Dialysis*
- *Exercise for the Dialysis Patient: A Guide for the Nephrologist*
- *Exercise for the Dialysis Patient: A Prescribing Guide*
- *Employment: A Kidney Patient's Guide to Working and Paying for Treatment*
- *Evaluation: Unit Self-Assessment Manual for Renal Rehabilitation*
- *Building Quality of Life: A Practical Guide to Renal Rehabilitation*

Life Options' online fact sheets include *Dialysis Answers*, over 100 fact sheets targeted to patients in their first 3 months of dialysis and those on dialysis from 4-12 months. Life Options has translated 12 popular easy-to-read 2-page fact sheets into Spanish on such topics as anemia, depression, the dialysis machine, exercise, fluids, hemodialysis adequacy, how to talk to your healthcare team, rehabilitation, restless legs syndrome, skin and hair problems on dialysis, traveling on dialysis, and vascular access. A license agreement is available to allow co-branding and printing of multiple copies of all Life Options print materials.

Patients or professionals can order *Feeling Better with Exercise: A Video Guide for People on Dialysis*, a 30 minute DVD companion to the exercise booklet for patients. Each DVD costs \$10 plus shipping.

Life Options conducts research on such topics as employment, knowledge of kidney-related subjects, long-term dialysis survivors' adaptation to kidney disease, nephrologists' and nephrology nurses' attitudes about renal rehabilitation, and the link between interventions and outcomes.

Life Options staff and consultants answer patients' and professionals' questions on message boards at [www.lifeoptions.org](http://www.lifeoptions.org), by email [lifeoptions@meiresearch.org](mailto:lifeoptions@meiresearch.org), and through the Rehabilitation Resource Center at (800) 468-7777.

Through its publications, programs and resources, Life Options is reaching out to the kidney community—and through research initiatives the kidney community is reaching out to the world.