

## U.S. Dialysis – How the System of Care Works

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### WHO OFFERS DIALYSIS

Dialysis in the U.S. – both home dialysis and in-center care – is provided through clinics that are certified by Medicare or the Veteran’s Administration. Also called “units”, “centers” or “facilities”, dialysis clinics must follow a set of Medicare regulations called the Conditions for Coverage that were first released in 1976 with a proposed update released for public comment in 2005 (they have been updated and public comment ends on May 5).

Each clinic is required to have the following staff, called the “care team” to provide care to home and in-center dialysis patients:

- A medical director
- Registered nurses (at least one present on each shift)
- A renal dietitian
- A social worker with a master’s degree

Clinics in every state except Montana also have dialysis technicians who provide care to in-center patients. Techs are required to have formal (book) training plus on-the-job supervision before they can provide care by themselves. After the training, each nurse may supervise three or more techs on each shift and each tech may care for four or more patients at a time. Five states (Arizona, California, Ohio, Oregon and Texas) require techs to be certified and pass an exam. Seven other states and the District of Columbia have laws that require certain training for techs (Connecticut, Kentucky, New Mexico, South Dakota, Virginia, Washington and Utah).

There are more than 4,400 Medicare-certified dialysis clinics in the U.S. and they are organized much like restaurants. About a third are either independent (think “mom and pop diner”) or small clusters of clinics with a single owner, often a doctor. A few clinics are still hospital-based, but most are free-standing. About two thirds of clinics are owned by large dialysis organizations or LDOs (corporate “chains,” like McDonalds). The largest LDOs in the U.S. right now are:

- DaVita – 1,200 clinics after its merger with Gambro
- Fresenius Medical Care (FMC) – 1,000 clinics

- Renal Care Group (RCG) – 415 clinics
- Dialysis Clinic Incorporated (DCI) – the largest non-profit chain, with 150 clinics.

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### DIALYSIS FACILITY COMPARE

Are you trying to locate a dialysis facility, or would you just like to know how your facility compares with others in your area?

The Dialysis Facility Compare (DFC) website, developed by CMS, gives detailed information about Medicare-approved dialysis facilities by state, city, county and/or zip code. It also gives comparisons for the clinical outcome measures of anemia, adequacy and mortality.

If you need additional help with a facility search or understanding the information on the page, please call the Network office using our toll-free patient number (877) 936-9260.

You can access the DFC website at:  
[www.medicare.gov/dialysis/home.asp](http://www.medicare.gov/dialysis/home.asp)

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Depending on where you live, there may be only one clinic, or you may have many to choose from. You can find out your dialysis clinic options on Medicare's website at:

<http://www.medicare.gov/Dialysis/Home.asp>.

On this site, you can

- Search for a clinic in the U.S.
- Learn how each one compares to others on key quality measures
- Download helpful checklists to take with you when you visit clinics or talk to clinic staff.

If you're looking for clinics that offer any of the types of home dialysis, visit our "Find a Center" database right here on Home Dialysis Central ([www.homedialysis.org](http://www.homedialysis.org)).

## HOW DIALYSIS QUALITY IS MAINTAINED

The most important thing for you to know about dialysis clinics is that they can differ – *a lot*. Most people choose a clinic based on where their doctor sends them, how close it is to home, or how easy it is to get to. But some clinics offer much higher quality care than others, and some clinics offer only one form of treatment – while others offer several types of dialysis so you have more options. You have a right to choose your doctor and your clinic (within the limits of what your insurance will pay for).

Getting good quality care is the most important way that you can have the best life possible on dialysis. There are a number of different ways that quality is monitored and improved in dialysis:

- State surveyors inspect each dialysis clinic to ensure that they follow the Medicare regulations. Inspections can be done at any time if there is a complaint. If no complaints are made, clinics get surprise inspections, as time is available. A U.S. General Accounting Office (GAO) study released in October, 2003 found that, while states are expected to survey all clinics within three years, only nine states met this goal. Five percent of clinics had not been inspected in nine years.

- Large dialysis organizations track the care given in their own clinics, and do continuous quality improvement (CQI) projects to help all of their clinics improve their patient outcomes. Independent clinics may also do CQI projects to improve care. Medicare Surveyors may ask clinics about their CQI programs when they do an inspection.

- The End-stage Renal Disease (ESRD) Networks, a set of 17 regional, non-profit dialysis oversight agencies, collect data, oversee quality and handle patient grievances. They track a set of "Clinical Performance Measures" (CPMs) of dialysis quality and report these back to the facilities. Networks also provide some patient education and encourage rehabilitation and do CQI projects.

You can find your Network at [www.esrdnetworks.org](http://www.esrdnetworks.org). You can go directly to ESRD Network 8's website at [www.esrdnetwork8.org](http://www.esrdnetwork8.org)

- Kidney Disease Outcomes and Quality Indicators (K/DOQI) Clinical Practice Guidelines put out by the National Kidney

Foundation address a number of areas of care. Based on a thorough review of medical research and the opinions of a national panel of experts, these guidelines form the basis for measuring the quality of dialysis medical care. The guidelines are a minimum. Care that meets – or exceeds – K/DOQI Guidelines is what you'll need to be looking for.

- National statistics on kidney failure, including patient age, gender and race; treatment type; cause of kidney disease; measures of quality; and much more, are collected each year and compiled into a resource called the United States Renal Data System (USRDS) Annual Report. These statistics are used to look at national and regional trends and assess whether dialysis care is getting better across the country.

You can download the USRDS report at <http://www.usrds.org/adr.htm>.

**The Network 8 web site made it through the operation!!!**



**Visit our web site at its new location:**

**[www.esrdnetwork8.org](http://www.esrdnetwork8.org)**

# Conquering Your Fistula Fear

## CONQUERING YOUR FISTULA FEAR

Deciding to get a fistula placed can be a lot like trying to stop smoking! Have you ever known something you should do, but for some reason you haven't been able to do it? Many dialysis patients hesitate to get a fistula placed because they are scared, anxious, or depressed. Some patients say, "What is my arm going to look like after this?" Other patients have a fear of having needle sticks. If these are some of your concerns, there are things you can do to take control and get a fistula placed!

What is anxiety? Anxiety and fear can be as general as a dread of the whole treatment process or as specific as a fear of needle sticks. You can explore and identify the anxiety and fear you may experience through discussions with your social worker and/or nursing staff. Below are some common anxieties and fears:

### Fear of dialysis treatment including needle sticks, blood loss, anticipated physical pain, and loss of control

#### What you can do:

- Ask questions.
- Address pain control with your Nephrologist. Ask:
  - *Is Emla (Lidocaine) Cream an option?*
  - *Would anti-anxiety medication help?*
  - *Is self cannulation an option (sticking yourself)*
  - *Can you learn the "buttonhole technique?"*
- Learn about relaxation exercises such as deep breathing. Practice them.

- Every patient experiences pain differently. Write down and keep track of your own "level of pain." Report your levels of pain to the Nephrologist.
- Know what your access should look like and feel like.
- Assist the staff with needle placement. If the person is cannulating you and it feels right say, "When you do it that way it feels right." If something feels wrong say, "When you do it this way, I feel more pain, etc."
- Talk to your Social Worker about your concerns and/or fears.

### Fear of the medical setting (dialysis unit, hospital, etc.)

#### What you can do:

- Ask questions such as
  - *Can I take a tour of the facility*
  - *Can you explain the different machines to me?*
  - *Can you explain the dialysis process to me?*
  - *Would anti-anxiety medication help?*
- Bring something from home (blanket, pillow, or book).

### Fear of health care providers (doctors, nurses, social workers, dieticians, technicians, etc.)

#### What you can do:

- Ask questions such as
  - *I am interested in learning more about the healthcare team.*
  - *Can you tell me your name?*
  - *What is your role here?*
  - *Are you a technician or a nurse?*
- If the facility allows, bring a

family member to orientation with you.

### What if I injure my fistula?

#### What you can do:

- Ask questions such as
  - *Are there any limits to using my arm?*
  - *What should I not do?*
  - *Is it okay to lift heavy things?*
  - *Is it okay to wear tight clothing?*

### Seeing my fistula is a reminder that my health is not good.

#### What you can do:

- Remind yourself that dialysis is life saving and you can live longer with a fistula.
- Accept that your fistula is the "best" access type.
- Remind yourself that the change in appearance is necessary.

### Lots of people ask "What is it?" and I don't know what to say.

#### What you can do:

- Consider this an opportunity to educate others.
- Coin a phrase:
  - *It's my access.*
  - *It helps keep me alive.*
  - *I have Chronic Kidney Disease.*
  - *I am one of 312,000 people in the United States who have End Stage Renal Disease.*

### I feel embarrassed about the way my fistula looks.

#### What you can do:

- Talk to your Social Worker about the way you are feeling.
- Some patients consider their access their "badge of honor" or "lifeline".

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## Conquering Your Fistula Fear

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- ❑ Some patients cover their access with loose wraps or a flowing sleeve.

If you have any of the concerns listed above, find comfort in the fact that you are not alone. Most patients can identify with at least one of these fears. All of these can be managed with education, medical treatment or by just having a conversation with your social worker and other health care team members. If you are able to take control and address your concerns about getting a fis-

tula, you will be improving your overall health and well-being.

*The information was gathered through a collaborative effort of Patient Services Coordinators from the 18 ESRD Networks across the nation. It is the first in a three part series that will continue to be featured in the next two issues of Network 8's Kidney Patient Update. If you would like more information on AV Fistulas please contact the Network office at 877-936-9260.*

### 2nd Annual KIDney Kids Retreat Provides Fun for Everyone

The National Kidney Foundation of Mississippi held its second annual KIDney Kids Retreat April 9 – 10, 2005 at the Henry S. Jackson Camp in Utica, Mississippi. Nine (9) children including two peer counselors and one little sister had a blast!!

The campers arrived at the camp on Saturday morning for registration and lunch. Following lunch, the group was taken out to the rope course to begin the activity phase of the camp. Many of the campers climbed all the way up to tower and several repelled across the field on the ZIP line. The parents were given an opportunity to discuss their concerns with Paul McGinnis, M.D., a psychiatrist who was a CKD patient all of his childhood before starting dialysis at

19. In addition to Dr. McGinnis, nurses and social workers were available to help answer questions. The evening activities included a talent contest, dancing and a bingo tournament. Sunday morning activities included arts and crafts. The kids had so much fun that they want the camp to last longer next year!



Pictured clockwise are Rodreakal Brown, 12, a transplant patient from Wesson; Mioshi Richardson, 13, CKD patient from Jackson; Kayla Armwood, 11, CKD patient from Jackson; Angelica Hatton, 17 hemodialysis patient from Collins – Peer Counselor; Zeno Aultman, 22, hemodialysis patient from Brookhaven – Peer Counselor; Mario Harper, 10, CKD patient from Jackson; Stephen Spears, 13, CKD patient from Clinton; Semaj Harris, 8, transplant patient from Jackson, Danella Harris, 7, little sister from Jackson.

### AAKP ANNOUNCES SITE OF 32ND ANNUAL CONVENTION

Take over the driver's seat in your healthcare by attending the nation's largest gathering of kidney patients and their families – the American Association of Kidney Patients (AAKP) Annual Convention. This year's convention, titled "Quality First: Patient's Driving Excellence," will be held Sept. 1- 4 in Las Vegas at the JW Marriott Las Vegas Resort and Spa.

AAKP anticipates its 2005 Annual Convention to be its largest, most successful event to date. The conventions offer attendees a unique opportunity to join and discover important information influencing their healthcare. During this three-day event, patient, along with their families and caregivers, can expect well-rounded topics for chronic kidney disease (CKD), dialysis and kidney transplant patients. In addition, the 2005 Annual Convention gives attendees the opportunity to come together and share their experiences.

The convention brochure, available in April, will include a registration form and detailed agenda, along with information on dialysis arrangements and travel discounts. AAKP members will automatically receive the Convention Brochure. To join the Convention mailing list, please send an e-mail to [info@aakp.org](mailto:info@aakp.org). For more information, please visit [www.aakp.org](http://www.aakp.org).

## To Work or Not to Work: That is the Question

by Brenda Dyson

I started dialysis in August of 1987. I was 32 years old and had just lost my mother 2 months previously. I had two younger sisters, Lisa was 25 and Lynda was 23 and they were my only close family members. I remember thinking that I simply had to keep working, there was nobody else to support me and I remember thinking that it wasn't going to be easy.

I was lucky for several reasons. My kidney failure was caused by Membranous Glomerulonephritis and there was nothing else wrong with me. I didn't have hypertension or diabetes or any of the comorbid conditions that these diseases can cause. I was essentially healthy except for kidney failure. I also had a college degree in Medical Records Administration. It doesn't take a whole lot of energy to work at a desk and that's a good thing because at the time I didn't have much energy (I started dialysis before EPO was available and worked most days with a hematocrit of 18 or 19). I also had a wonderful kidney doctor who immediately agreed with me that continuing to work was the best medicine that I could possibly take.

He told me about home hemodialysis and how this was a wonderful modality for people who want to continue in the work force. My sisters agreed to be my helpers and we were all trained on the machine. Another good thing about home dialysis therapies (both hemo and peritoneal dialysis) is that Medicare becomes effective immediately and you don't have the 3-month waiting period and this was very helpful with all my hospital bills.

Working has been the best thing possible for me. It has kept me active and busy, it's gotten me involved in volunteer organizations and I've met many inspirational people. It's now been almost 18 years since I've started dialysis and I've worked through getting

a transplant in 1990, losing that transplant in 2001, re-starting dialysis and being trained on the NxStage Daily Home Hemofiltration system in 2002, and receiving a second kidney in July of 2002.

It has helped to have an understanding boss and a stubborn nature. If you want to continue to work, don't let anybody talk you out of it; simply ask them to help you look for ways to make it possible.

One way to help is to contact your state's Vocational Rehabilitation Agency.

In **Alabama** contact the Department of Rehabilitation Services  
Phone: (334) 281-8780.  
The website is [www.rehab.state.al.us](http://www.rehab.state.al.us)

In **Mississippi** contact the Department of Rehabilitation Services  
Phone: (601) 853-5100.  
The website is [www.mdrs.state.ms.us](http://www.mdrs.state.ms.us).

In **Tennessee** Contact the Tennessee Agency Department of Human Services, Division of Rehabilitation Services  
Phone: (615) 313-4891.  
The website is [www.state.tn.us/humanserv/rehabilitation](http://www.state.tn.us/humanserv/rehabilitation).

Other helpful links about working include the Life Options Rehabilitation Program at [www.lifeoptions.org](http://www.lifeoptions.org) and the Ticket to Work Program at [www.yourtickettowork.com](http://www.yourtickettowork.com).

Additional information on home dialysis therapies can be found at Home Dialysis Central's website at [www.homedialysis.org](http://www.homedialysis.org).

## Network 8 Unveils New Grievance Poster

In February, Network sent new grievance posters to all of the facilities in the Network. This poster lists our toll-free phone number along with the toll-free numbers of the State Survey Agency for your state. We hope that you have seen these posters in your facility and if you haven't, please ask your social worker to check and see why they haven't been posted. A sample poster is listed to the right.

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**Have a problem?**

If you have a problem in your unit, here are some steps you may take:

1. Talk to your social worker, head nurse, administrator, or doctor; and
2. Follow the steps of your facility's grievance procedure.

If the problem continues, you should contact:

<b>Your ESRD Network</b> Network 8, Inc. P.O. Box 55868 Jackson, MS 39296 1-877-936-9260 Email: <a href="mailto:info@nva8.esrd.net">info@nva8.esrd.net</a>	<b>OR</b>	<b>Your State Agency</b> Division of Health Care Facilities Alabama Dept. of Public Health ATTN: Complaint Dept. 201 Monroe St., Ste. 600 Montgomery, AL 36104 1-800-356-9596
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## Network 8 Unveils New Grievance Poster

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ESRD Complaint and Grievance Process - Under Federal Medicare Law, ESRD Networks are authorized to implement procedures for evaluating and resolving patient complaints or grievances about the quality or adequacy of the care that you receive in your dialysis facility.

If you have a complaint about the quality of the care that you are receiving, your FIRST step should be to discuss your problem with your social worker, physician, nurse or facility administrator. These discussions with your caregivers may be all it takes to resolve your problem.

If these discussions do not resolve your problem, Network 8 may be able to assist you in resolving your complaint or grievance by providing an impartial review of the situation. You always do have the option of calling the Network before discussing the issues with your caregivers if necessary.

Should you need more information about how the Network complaint and grievance process works, talk to your facility social worker or call the Network at 1-877-936-9260. The information is also available on the Network 8 website at [www.esrdnetwork8.org](http://www.esrdnetwork8.org).

As is stated on the new grievance poster, there are other resources that can help you deal with concerns in your dialysis facility. They are the State Survey Agencies. These agencies are responsible for making sure that your clinic complies with the Medicare standards for dialysis centers. Both Network 8 and the State Survey Agencies investigate complaints as one of their many services. The phone numbers for the State Survey agencies are:

- Alabama - 800-356-9596
- Mississippi - 800-227-7308
- Tennessee - 877-287-0010

## The 20 Year Club

*The 20 Year Club is a continuing feature of Network 8's Kidney Patient Update. This feature highlights Network 8 patients who have survived End Stage Renal Disease for 20 years or more. If you or someone at your facility has been on dialysis, had a transplant, or a combination of both for 20 years or more, please let us know. Contact Brenda Dyson at Network 8 at 877-936-9260 or fax the information to 601-932-4446. The mailing address for Network 8 is P.O. Box 55868, Jackson, MS 39296-5868. The following articles were submitted by Arnitta Pryor, LMSW. The new members are all patients of Dr. Thomas Wooldridge and all have lived at least 29 years on dialysis.*

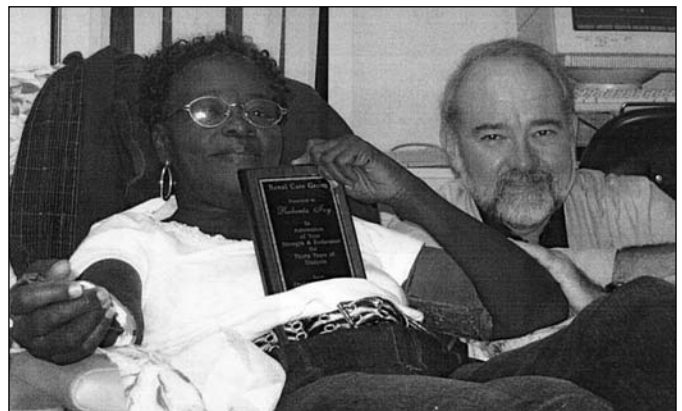
### Thirty Years and Blessed – Roberta Ivy

Hello, my name is Roberta Ivy and I am a dialysis patient. I have been receiving treatments on Tuesday, Thursday and Saturday for the last thirty years. Through the blessings of God and strong family support, I continue to live each day to the fullest and enjoy life. Thank you for giving me this opportunity to tell you about myself and how I have been blessed during my thirty years on dialysis.

I was born November 26, 1949 to Mitchell and Alberta Joiner. I attended school for a while and later had to quit to help support my family. In the fall of 1969, I got married to Robert "Bally" Ivy. We have two children, a girl named Lisa and a son named Robert. In the summer of 1974 I got real sick and went to the hospital. Dr. Wooldridge was my doctor. I stayed with a lady in Jackson, MS and received my dialysis treatments there for two weeks. After that I was transferred to Tupelo, MS for a while and now I run in my hometown of Oxford, MS. In 1983, I got a divorce, moved in with my father and I am still living there now. I worked as a housekeeper for private

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*Roberta Ivy with Dr. Wooldridge*



homes up until 1998. I was forced to quit due to the work and the treatments.

My family and God are two of the most important things that have kept me going through the tough times. Waking up each day and being able to receive these treatments are blessing from God that I cherish each day. The strong support that I receive from my family allows me to continue to thrive each day and go forward in life. I have three wonderful grandchildren, Stantavias, Keyshawn and Audrianan that are the pride and joy of my life. They keep me on my toes and on the go all the time. They also make sure that I take my medicine on time and eat the right foods.

The other two important things are the nurses and the doctors. I love all the nurses and doctors who have treated me over the years. Without their loving and caring support, it would have made my transition very stressful. Thank you all for everything you have done for me over the years.

Some people look at dialysis as being a burden, but I have realized that without it, I wouldn't be alive today.

### **Ethel's Longevity With Dialysis**

Ethel Rogers began dialysis December 1, 1973. She remembers when dialysis treatments were 12 hours, 2 days per week. She celebrated when her time was cut to 9 hours for the first time. Ethel had a graft placed in her forearm that lasted about 3 years. In 1974 a left lower arm fistula was created and she is still using it today. Ethel started home hemodialysis in

November of 1983. With the help of her mother, she was able to continue home dialysis for 13 years. After suffering a stroke, she began incenter hemodialysis at the Eupora dialysis facility in February 1996 under the supervision of Dr. Thomas Wooldridge.

Ethel has a very supportive family. Her now elderly mother, son and four grandchildren are always around to help out as needed. Ethel states, "My faith in God has brought me through the hard times." "My doctors in Tupelo, MS are great. They always take time with me and make me feel special". The RCG – Eupora staff enjoys taking care of Ethel because she always greets them with a smile.

*Ms. Ethel Rogers*



### **Williard "Dan" Murphy's Dialysis Journey**

Mr. Willard "Dan" Murphy has had quite a journey in the world of dialysis. According to him, he was born with Tubular Sclerosis which he inherited from his paternal and maternal grandparents. His kidney failed in November 1976 and he was referred to the University Medical Center in Jackson, MS where he met Dr. Thomas Wooldridge. Mr. Murphy began hemodialysis in Jackson. He

traveled from Columbus, MS to the Medical Center in Jackson three days a week until he transferred to the dialysis unit in Tupelo. The trip from Columbus to Jackson took about three hours where the trip to Tupelo took 1½ hours.

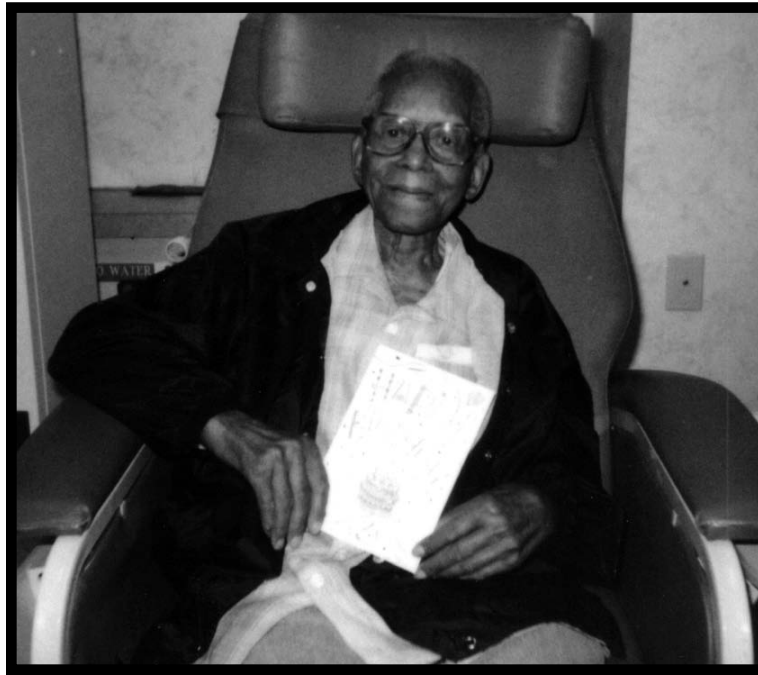
In 1977, Mr. Murphy received a transplant but later rejected within 2 weeks. He dialyzed in Tupelo for 2 to 3 years until Dr. Wooldridge suggested he get into the home hemodialysis program. In order to start the home program he had to travel back to Jackson for three months. His mother was his helper and he trained on a Cobe Century 2 machine. He dialyzed at home for nine years until he received a transplant on May 10, 1986. His mother states that Dan's transplant was the best Mother's Day gift she has ever received.

The kidney lasted for 17 years and 2 months before rejecting. Dan began hemodialysis once again on August 9, 2003. Dan states that he has been amazed at the changes in dialysis machines. The automatic functions of the current machines are advanced from all the manual tasks he had to perform on the Century 2. Dan credits his successful life on dialysis to God, his family, Dr. Wooldridge and the kidney unit staff. He currently dialyzes at the RCG – Aberdeen unit.

*Mr. Dan Murphy*



*In Memoriam  
Mr. Claude Washington*



Mr. Claude Washington, the 2nd oldest dialysis patient in the United States, passed away on February 19, 2005. He was 103 years old. Mr. Washington was born on August 31, 1901 and started dialysis on April 15, 1997. He was a dialysis patient for almost 8 years.

Mr. Washington lived all over the United States. At the time of his death he was living with his daughter in Chattanooga and was a patient at the DCI Lyerly facility. Mr. Washington maintained good health for most of his life, and for many years after starting dialysis, would occasionally walk to his dialysis treatment. He wrote several books on race relations and had two books published at the age of 96. He was an amazing man and will be greatly missed by his family and friends at DCI.

In the U.S. there was one patient two months older than Mr. Washington, but he has been on dialysis for only two years. Last year there were thirty-three (33) active centogenarians on dialysis in the U.S. Three were on home modalities, the rest were on in-center hemodialysis.

Pictured is Mr. Washington on his 103rd birthday.

**NETWORK 8, INC.**

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PATIENTS ONLY: 877-936-9260

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**NETWORK 8** is available to answer any technical or treatment related questions that you may have. You can call our toll-free phone number (for patients only) or e-mail us at: [info@nw8.esrd.net](mailto:info@nw8.esrd.net).