



KIDNEY PATIENT UPDATE

SERVING RENAL PATIENTS IN ALABAMA, MISSISSIPPI AND TENNESSEE

SPRING 2004

NETWORK 8 IS HERE TO HELP YOU 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.

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WHO HAS THE LONGEST WORKING FISTULA? THAT'S RIGHT FOLKS - A NEW CONTEST!!!

As the judges were reading the essays sent in for the "Why I Love My Fistula" Contest, it was noted that Carolyn Taylor of Dayton, TN has had the same working fistula for the past 29 years!! Is this the longest working fistula in our Network? We want to find out.

We are asking for every patient who has had the same fistula for 15 years or longer to please let us know. Just ask your facility staff to fax, e-mail or mail us your information, letting us know your name, when you started dialysis, where you dialyze and how long you've had your fistula. The top ten patients with the longest lasting fistulas in our Network will be recognized in the Fall issue of Kidney Patient Update.

Please help us find the winners. You can fax your information to (601) 932-4446; e-mail me at bdyson@nw8.esrd.net; or mail your information to Network 8, Inc., P.O. Box 55868, Jackson, MS 39296-5868.

HOW DOES YOUR DIALYSIS FACILITY COMPARE?

The Centers for Medicare & Medicaid Services (CMS) has an important tool available for you on the Internet called Dialysis Facility Compare. This resource gives you detailed information about Medicare certified dialysis facilities, and lets you compare facilities in your area. The information helps you compare facility characteristics and quality measures.

Dialysis Facility Characteristics include:

- Name, address and telephone number of the facility,
- Date the facility first received Medicare certification,
- Shifts starting at 5:00 p.m. or later,
- Number of treatment stations, and
- Types of dialysis offered.

Quality Measures include:

- Percent of patients at a facility who receive adequate hemodialysis,
- Percent of patients at a facility treated for anemia (low blood count), whose anemia was adequately managed,
- Patient survival information.

Dialysis Facility Compare also has other resources and features regarding the treatment of kidney disease. Please visit www.medicare.gov/dialysis/home.asp to learn more.

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NETWORK 8 ANNOUNCES THE WINNERS OF THE FIRST ANNUAL "WHY I LOVE MY FISTULA" CONTEST

Grand Prize:

Bobby Riggs - DCI Knoxville

Honorable Mentions:

Carolyn Taylor - DCI Dayton

Julius Cszaszar - Hattiesburg Clinic Dialysis

Eddie W. Mason - GAMBRO - Memphis

These four essays are printed in their entirety in this issue of Network 8's *Kidney Patient Update*. We would like to thank all of the patients who sent in essays. You are all winners!! The judges enjoyed reading all of the essays and did have a very difficult time in narrowing the winners down to four. We encourage everyone to continue to be involved with Network 8 and to participate in the contests that are run in *Kidney Patient Update*.

Back!

"THE DOCTOR IS IN AND HE'S MADE THE 20 YEAR CLUB!"



Our Physician columnist is Paul McGinnis, M.D. Dr. Paul is a kidney transplant recipient and a graduate of the University of Mississippi School of Medicine and is currently the Senior Staff Psychiatrist at Mississippi State Hospital. Dr. Paul will be happy to answer questions related to problems ESRD patients face in simple everyday language. Please send any questions, comments or topics for discussion to Brenda Dyson, Network 8., P.O. Box

55868, Jackson MS 39296-5858

This issue Dr. Paul will not be answering a question, but is celebrating his inclusion in "The 20 Year Club"!

I finally made it! This is my entry into the 20 year club. It seems for the last 3 or 4 years that at least 20 years had gone by already. Over the past 20 years I've had probably close to 25 operations and three of these were kidney transplants. The last transplant has been doing well for eight years. Along the way I have also done CAPD, CCPD, Incenter hemodialysis, the only thing I haven't done is home hemo. In reality my problems started as an infant which was 39 years ago. Although officially it's been 20 years on renal replacement therapy. During that time I've completed college, medical school and a residency in psychiatry. In no way would I want anyone to believe that this has been an easy time. There have been many hard times along the way, the most recent of which was this fall.

On September 11, I was hospitalized with a supposed sinus infection. Two days I was in the Intensive Care Unit with a real diagnosis of West Nile Virus. I did not leave the hospital until the 12th of December. This was one of the hardest things that I have ever had to go through. It is not the first nor will it probably be the last time that I am challenged by my illness. Our lives with chronic kidney disease are often difficult, but you can overcome almost any obstacle. There is nothing special about what I've done. I have just played the hand that I've been dealt. It is something that all of you can do. Of course, it's true that your life will be harder now, but there's no reason that it can't be full and enjoyable. Yes, there will be setbacks and problems in your life, but they don't have to be the end to a happy life.

After this last hospitalization I was unable to move. I could not lift my hands from the bed. It took several months of rehabilitation and now I am able to walk on my own, drive and have started back to work. This is to say it sometimes takes a lot to overcome the obstacles that life puts in your path, but anything is possible. Throughout all of this, my transplanted kidney has done well. And I expect it will last for many more years!

We need to live life each day as best we can. We need to make sure that our lives are full of friends, of family and love. We do not need to live our lives around our illness, but around those things that give us joy and make life worthwhile. You can't do this if you continue on in bitterness, mourning the many losses that you have had. Chronic kidney disease and its problems should just be bumps in the road that you have overcome and have left behind you in the past, not something that shapes your daily lives.

P.S. Dialysis patients also have a depleted immune system, just like transplant patients, so stay away from those bloodsucking, germ-carrying mosquitoes!!

"WHY I LOVE MY FISTULA" CONTEST GRAND PRIZE WINNER

"A FISTULA FULL OF DOLLARS"

By Bobby Riggs

At first it seemed almost ridiculous to write an essay on why I loved my fistula. It actually seemed to make more sense to write about why I hated my fistula, with its unnatural bumps that allowed me to have dialysis three times a week, four and a half hours a day. What exactly was there to love about it anyway?

But as I started thinking back upon the last 16 months of dialysis, it brought back to me some of the more difficult emotions that dialysis had caused me. The deeper I delved into that process and what it meant for me and my life, the more I realized that there might be someone out there who might need some straight talk about this aspect of dialysis.

Before using the fistula, I had a temporary entry in my chest. It seemed to work well enough, until I understood the dangers of a nearly open wound in my chest, a wound where the tube was inserted in my skin where it was susceptible to infection. Infection was the reason why I had to sit there and watch as the nurses worked so hard to keep the area clean. One slip and I could end up back in the hospital. As anyone involved with kidney failure can tell you, going to the hospital can grow old.

A fistula affords the patient a wide and tough area where he can be repeatedly stuck for the purposes of dialysis. In my case, I did not fully face all of these details. I was given exercises to toughen up the area, but I was feeling sorry for myself and the fact that poor old me had to be on dialysis. The first time I was stuck and the first time my fistula was used, I felt more like a stuck pig rather than a human being, I was depressed.

But, as it often does, a light soon dawned within my stubborn head. This entire process was for me, was to keep me alive - and not just for me. There were other interested people who wanted this process to work, like my family. Even if, in my depression, I forgot about how others were feeling about my life and situation, I needed to wake up and include others in my thinking.

So as I began focusing on my life and trying to refashion it into the best framework for my future, I started to look at the details. This fistula and this strange strong pumping in my wrist, was the best and strongest entryway for dialysis, or for the process that was keeping me alive, one session at a time, four and a half hours a day.

As soon as I was able to move past my selfishness and realize that my life belonged not just to me, I saw that I had a responsibility to live life with the highest quality possible. That meant using this amazing technology that my fistula affords.

"WHY I LOVE MY FISTULA" CONTEST HONORABLE MENTION

By Carolyn Taylor

My name is Carolyn Taylor and I have been on dialysis for 29 years. During this time I have never had a transplant or tried any other modality other than hemodialysis.

I am writing this letter to enter the contest on the Fistula First Essay. First of all, I have had my fistula for 29 years. Yes, the very same one I had when I began dialysis 29 years ago.

During the years I have been on dialysis, only twice have I had problems with my fistula. Once during a carpal tunnel surgery, the surgeon left the tourniquet on too long and clotted it off. The other time I was having problems with my blood pressure and my fistula clotted off. Both times they were able to declot it and it worked perfectly!

I believe it is better than other types of accesses because it is your own natural vein and artery. Because it is your own natural vein and artery, it can lead to better clearances than other types of accesses. I know my KT/V is better than a lot of patients and I think it is due mainly because I have a fistula. My KT/V runs 2.11 & 2.35 most of the time. My belief is that it is because of the fistula producing such a good blood flow.

I have seen a lot of different types of accesses during my 29 years. I would not have anything else but a fistula unless there was just no other alternative. All other accesses seem to clot off more often and become infected more readily than a fistula.

I would like to add this little true story.

When I first started dialysis 29 years ago, I attended a Bible Study group. Attending that night was a little old lady whom I did not know. She looked at my arm, and having no idea what was wrong with my arm, asked if I would not mind if she prayed for my arm. I told her sure go ahead. Well, she prayed a simple little prayer, telling God she didn't know what was wrong with my arm, but to please touch it and take care of it. I have and always will believe that that prayer has kept my fistula running and in good shape for these 29 years!

"WHY I LOVE MY FISTULA" CONTEST HONORABLE MENTION

By Julius Csaszar

Julius Csaszar is a patient at Hattiesburg Clinic Dialysis in Hattiesburg, MS. In his cover letter for the contest he stated: "My name is Julius Csaszar. I am a 44-year-old hemodialysis patient at the Hattiesburg Clinic Dialysis Unit. Remembering my confusion and apprehension when I was first diagnosed with ESRD, I thought it would be helpful to new and future dialysis patients to relate my experience with a fistula. I had a fistula installed in my left forearm by my vascular surgeon in the spring of 2000 and it has been flawless since then. So, if I can be of any help to other patients, please use my essay".

I picked up a copy of Network 8's Kidney Patient Update the other day and the ad for an essay about how I love my fistula caught my attention. It also caught me off guard because I suddenly realized that I had probably been taking my fistula for granted. I guess I had taken it for granted because it works so great. My fistula has been absolutely trouble free for almost 4 years.

After losing total kidney function to polycystic disease, the great medical team at Hattiesburg Clinic strongly suggested an AV fistula for my permanent access. Their examination proved that I was a good candidate and being relatively young (40 years old), a fistula should serve me well.

And serve me well, it has.

The essay contest suggests we tell how we love our fistula. Well, before, I never would say I actually loved it. Its not very attractive and careful care has to be taken to protect it, but I sure know it loves me. It's my life-line. My ultimate blood brother, if you'll pardon the pun.

My fistula and the fantastic staff at Hattiesburg Clinic Dialysis Unit are the reasons that I am alive today. Without both of them working so well together, I would be in a world of trouble. They have preserved my quality of life.

For every Pro there is a Con. In the reality of ESRD, a fistula is the Pro to have on your side working for you.

"WHY I LOVE MY FISTULA" CONTEST HONORABLE MENTION

By Eddie W. Mason

In the early spring of 1982, I began to develop kidney failure. My doctor recommended that I have a fistula placed in preparation for dialysis. I had an A-V (arterio-venous) fistula placed in my left arm in March 1982. Following surgery, I had a chance to exercise my arm and allow my fistula to grow stronger over several months before use.

In August 1982, after developing complete kidney failure, I began hemodialysis twice weekly, and then later three times weekly. This has been the only dialysis access that I have had since my fistula was place in 1982! It has never been infected, and the sites where the dialysis needles are placed are no longer painful when stuck.

The other nice feature of my fistula was the fact that I was able to work part-time without fear of the area becoming infected.

So, as you can see, I really love my fistula since it has been trouble-free after 21 years of use. I would highly recommend this type of access for hemodialysis.

DIET, EXERCISE AND GOD GET THE CREDIT

*This article was written by Stephanie Nichols for the March 15, 2004 issue of The Commercial Appeal in Memphis, Tennessee.
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Eleven years ago, Ylonda Watkins was told she needed a new kidney.

Then she was told she didn't qualify for a transplant. She didn't meet the weight requirements.

At only 25 years old, it was hard to deal with the reality. But it wasn't enough to make her change.

"You'd think that saving your life would make you lose the weight, but it didn't," Watkins said. "I didn't see the long-term effects, even though I knew my survival depended on me changing."

So, instead of making an effort to lose weight, Watkins settled for undergoing hemodialysis treatment three times a week, four hours per session.

"After years and years of this regimented lifestyle, I became tired. I felt as if something was missing from my life but I had no drive to change it," Watkins said. "I have always had a true belief in God and Jesus Christ, but for some reason I never developed a true relationship with Him. Two years ago, I started going to church. There, my faith in the Lord grew, my desire to know His word grew, and my strength in the Lord grew. I now had a higher power to look to for help."

Las April, weighing 283, Watkins was 55 pounds away from qualifying to be put on the transplant list. She was introduced to the Weight Watchers points system.

"I knew I had a long way to go, but I would set small goals for myself," she said. "I found the program to be fun and exciting, not to mention the fact that it was really working. After seeing that the diet was really working, I became inspired. I was doing so good with no exercise that I wondered what would happen if I incorporated a little exercise."

Watkins began working out at the Hope and Healing Center three times a week.

"When I first started exercising, I got on a treadmill and walked for 20 minutes at 2.6 miles per hour and I literally thought I was going to die. I really felt like I was going to faint," she said. "But now, I'm up to 40 minutes at 3.7 miles per hour and walking up an incline. I get to going so fast that I feel like I'm walking underground!"

In June, she added strength training. In nearly 11 months, Watkins lost 67 pounds, putting herself 12 pounds below the weight limit to qualify for the transplant list. But she is not through.

"Right now, my goal weight is 180; well, that's my short-term goal," she said.

Watkins doesn't credit her success entirely to her efforts.

"Realizing what I needed and how to do it was like putting together a puzzle," she said. "It was like all along I knew I needed to do something about my weight so I could live longer. But it took finding the one missing piece of the puzzle - God - and it all came together. I guess you could say I work up and started living."

NETWORK 8 IS HERE TO HELP YOU ESRD Complaint and Grievance Process

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Other resources that can help you deal with concerns in your dialysis facility are the State Survey Agencies. These agencies are responsible for making sure that your clinic complies with Medicare standards for dialysis centers. Both Network 8 and the State Health Departments investigate complaints as one of their many services. The phone numbers for the State Survey Agencies are:

Mississippi - 800-227-7308

Alabama - 800-356-9596

Tennessee - 615-742-7221

REHAB RESOURCES

The last issue of Kidney Patient Update contained the article "What Is Rehabilitation?" As the article stated, rehabilitation is not just about returning to the work force, it's about leading as active a lifestyle as possible. But, for those of you who are interested in returning to the work force and need to know your options, you should contact (or have your social worker contact) your state's Vocational Rehabilitation Agency.

The Agency in Alabama is: Dept. of Rehabilitation Services
Phone: (334) 281-8780

The Agency in Mississippi is: Dept. of Rehab Services
Phone: (601) 853-5100

The Agency in Tennessee is: Dept. of Human Services
Div. of Rehab Services
Phone: (601) 313-4891

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KIDNEY PATIENT UPDATE is a quarterly publication of Network 8, Inc. CMS Contract #500-03-NW08. Letters and articles for submission are welcomed and may be sent to Network 8, Inc.

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.