



# ESRD Network 4, Inc.



: Working for you

## Network News For patients, families and caregivers

### Focus on Fistulas

In 2003, Medicare and the End Stage Renal Disease Networks began a nationwide project to help patients get the best possible vascular access for treatment. The goal of this project, called **FISTULA FIRST**, is to encourage the selection and placement of more fistulas. Surgeons and Nephrologists say that the fistula is the best vascular access for the following reasons:

- They are less likely to clot or get infected than the grafts and catheters.
- Once the fistula is developed and working, it will last longer than grafts or catheters.
- Most people with fistulas experience fewer hospital visits and surgeries for access problems.

The following article has been provided by a health care professional who is also an ESRD patient.

### A Patient's Perspective

**"A well functioning dialysis access is the key to successful long-term dialysis."** I first heard this when I was a 21 yr old neophyte and my nephrologist was explaining his choice for the type of access I was going to receive. At the time, I was feeling very fit and vigorous, but the blood tests showed highly elevated BUN and creatinine levels elevated to the point that it was decided that a gortex graft would be more expeditious and therefore more desirable. At that time I gave it very little thought because all I cared about was the end of my fledgling baseball career. Little did I know how big a part of my life my dialysis access would become!

When I was asked to write this article, I jumped at the chance because I really believe in the importance of knowing your access and how to keep it operating properly. But I must admit I found this concept difficult to write about. Vascular access technology has changed drastically in the 21 years since I started dialysis. There are so many choices and techniques to

*(Continued on page 2)*

Spring 2004

#### Special points of interest:

- ☺ Cover Story - An ESRD patient shares his personal experience with a Fistula access
- ☺ Network 4 sponsors a contest to find the patient with the longest lasting Fistula access
- ☺ An explanation of the ESRD Complaint and Grievance Process

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## Focus on Fistulas: A Patient's Perspective - Continued

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choose from. How do I cover all the options and choices in a useful manner? Should I interview professionals? Which materials should I use for my research? Then suddenly I realized, this is not about vascular accesses, this is an article about freedom and control. Freedom to decide what works for you and control over your overall dialysis treatment.

Over the years I have come to understand that dialysis works best when we have a measure of control over our dialysis and our lives. I gained this control in part due to the access I am currently using for dialysis. **My current access is an AV (arterio-venous) fistula.** This access replaced the first four accesses I had which were gortex grafts. All four gortex grafts were placed in my left arm and while they had the advantage of immediate usability, I found myself in the operating room far too often for my tastes. You see, although I was on dialysis, I still needed to indulge my two greatest passions - baseball and weightlifting. These two activities have kept me healthy both mentally and physically for the last 18 years. But I also had to live with the spectre of frequent de-clotting and graft revisions. This was due primarily to the drop in blood pressure caused by my active lifestyle. At least that was what I was told. I had begun to accept the reality of frequent de-clotting when my Nephrologist suggested an AV fistula. I was told that it would take some time to develop after it was created but that once developed, it would virtually eliminate the need for de-clotting surgery.

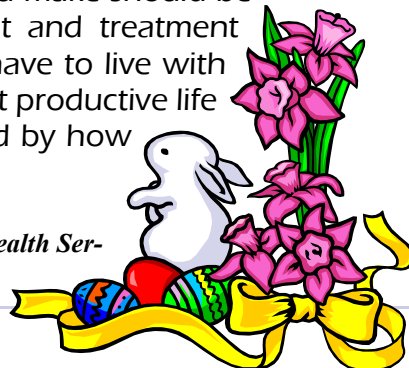
And it was true! **In the last 8 years I have had zero revisions and zero de-clotting procedures.** I still check my access daily, but it is such a joy to know that I can pursue my passions without the fear that at any time I may have to report to the emergency room for a graft de-clotting procedure of some kind.

I want to stress that while I am so very happy with my fistula, this may not be the choice for you. There are many factors which go into the choice of dialysis access, but I firmly believe that the most important factor should be the wishes of a well-informed and knowledgeable patient who has all the facts. This process is the first step in being in control of your dialysis, a process which I hope will lead to you to learn to put in your own needles!

Self-cannulation is a touchy subject in many units but as a patient who has been cannulating himself for 18 years I feel comfortable saying that it is the best decision I ever made. Self-cannulating is a skill which, once learned, will provide you with a significant measure of control over your day to day dialysis treatments. Ask your staff or following physician if you can self-cannulate.

To conclude, there are many options for receiving dialysis today including many types of vascular accesses and cannulating techniques. While I am thoroughly satisfied with my AV fistula, for the reasons previously stated, an AVF may not be for you. The choices you make should be well informed and should come after consulting your Nephrologist and treatment team. But ultimately your treatment choices are up to you and you have to live with them. So choose well and while you're at it choose to live the best most productive life you can. Remember we are not defined by our illness, we are defined by how we live our lives!

*Phillip Cade is a Legislative Liaison for the Washington State Department of Social and Health Services, and a Patient Services Consultant to Northwest Renal Network 16.*





# Award for Longest Lasting Fistula!



To Qualify:

- Must be a hemodialysis patient
- Must have an AV Fistula
- Must receive your treatment in Pennsylvania or Delaware

Do you think you have had a fistula longer than anyone else in our Network area? If so, fill out this form, fold and seal (tape or staple) place a stamp on it and return it to Network 4.

If you are the patient who has had an AV Fistula for the longest time, you will be eligible for a prize and recognition at our Annual Fall Coordinating Council Meeting, October 21, 2004 in Philadelphia, PA.

All travel expenses will be paid to attend! To qualify, the fistula may have had a revision or intervention, but must be the original fistula created.

Contest entries must be received by August 31, 2004

## Response Form

I Have an AV Fistula Access

\_\_\_\_\_  
Signature

May we use your name in the Network News and a poster that promotes AV fistulas?

YES       NO

What is the date your last AVF was created?

\_\_\_\_\_

May we contact your dialysis facility to verify this is correct?  YES  NO

\_\_\_\_\_  
Name

\_\_\_\_\_  
Address

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_  
Phone number

## AM I NORMAL? Part Four

A Series Written by: Eileen Zerbe, MSW, Renal Care Center of Christiana

This is the fourth of a series of articles exploring some of the feelings of persons living with dialysis. The first three articles pointed out that being diagnosed with kidney disease is a major event requiring permanent changes in almost every aspect of one's life. Having feelings in reaction to renal failure is NORMAL for both the patient and members of their family. The first three articles discussed denial, anger, and depression as common reactions to a chronic illness. This fourth part of the series explores how renal failure affects sexuality.

Sex can be a difficult topic for most of us to bring up. We feel uncomfortable talking about the subject, but it is important for us to know that the physical and emotional changes associated with renal failure can indeed affect a person's sexual desire and/or ability. In fact, 75% to 90% of patients on dialysis experience reduced sexual interest or ability. For men, impotence or the inability to attain or maintain an erection may occur. Women may experience difficulty with arousal. Both men and women may show a lack of interest, which can strain a relationship.

These sexual difficulties can be due to one or a combination of factors. Psychological factors often contribute to the problem. Depression, loss of job and role in the family, and the

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to yourself and to others.**

other stresses of dealing with a chronic illness all can be important causes of the problem. Other factors include the side effects of medications, reduced blood flow throughout the body, diabetes, and hormonal changes associated with uremia.

If you are experiencing sexual difficulties, most importantly realize that you are not alone and you are NORMAL. Although it is perfectly safe for kidney patients to engage in sexual intercourse, most dialysis patients do face some problems. Secondly, know that you may be able to help yourself by taking greater control of your disease. It will help you feel better about yourself and your body. By adopting a positive attitude, you may feel more attractive to yourself and to others. Also be aware that the medical community can offer some help in the form of drugs, surgical procedures and counseling. If you are interested in exploring some of these solutions, speak to your doctor.

## Make Vascular Access Your First Choice

There are several types of hemodialysis accesses available to patients.

*Arteriovenous fistulas (AVF)* are the preferred access for hemodialysis patients. Fistulas have fewer infections and access-related hospitalizations than other access types.

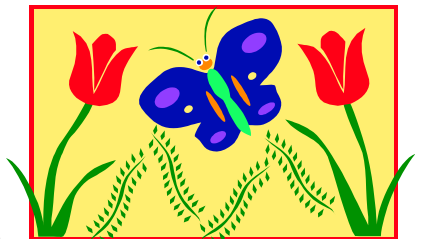
*Arteriovenous (AV) grafts* can be used within just a few weeks of placement. However, grafts are at higher risk for complications, infections and clotting.

*Catheters* may be used immediately after placement but are generally intended for short-

term use because of their high incidence of

complications such as infection and clotting, thrombosis and low flow rates. Catheters should be used ONLY when other accesses are unavailable to the patient.

Although all patients cannot have an AV Fistula, you should ask your nephrologist if an AV fistula is right for you!



## Working for you: Patient Services Coordinator and Network News Editor



### Dean Morris, Joins Network Staff

To the patients and families in Network 4, serving Pennsylvania and Delaware:

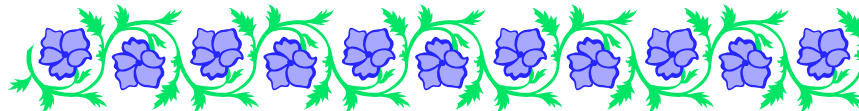
My name is Dean Morris and I am the new Patient Service Coordinator at the Network 4 office. I am a licensed Social Worker with 12 years experience assisting patients in a number of health care settings.

I'm a graduate of Case Western Reserve University in Cleveland, Ohio and I began my social work career there in the Cleveland Metropolitan Hospital as a trauma and intensive care center counselor.

I have a diverse background in case management working with patients and families in urban, suburban and rural areas. My most recent position was the Volunteer Director at a small community hospital in Latrobe, Pennsylvania. Latrobe is also my hometown

and the neighborhood where "Mr. Rodgers", Arnold Palmer and Rolling Rock Beer all began.

I look forward to serving you or your family member, if there are concerns or grievances you wish to discuss. I can be reached by dialing toll free at 1-800-548-9205



## Is Home Dialysis an Option For You?

Not all dialysis treatments occur in the outpatient dialysis unit. At least 380 patients in Network 4 do home dialysis – either home hemodialysis or Continuous Ambulatory Peritoneal Dialysis (CAPD).

Patients who dialyze at home on hemodialysis have received special training and are assisted by a family member or friend who has also been trained. Medicare will provide a dialysis machine for your home and provides reimbursement for part of the costs associated with training, supplies, and certain home support services.

CAPD requires no machine, and exchanges can be done at home or in any clean, well-lit place. With CAPD, your blood is always being cleaned. The dialysate passes from a plastic bag through a catheter and into your

abdomen. The solution stays in your abdomen with the catheter sealed. After several hours, you drain the solution back into the bag and start over again with a fresh bag of solution.

Advantages of home dialysis include the freedom to dialyze when you want to and not have to worry about the dialysis unit's schedule. If you are a new patient and receive home dialysis training in your first three months, then the three month waiting period for Medicare coverage will be waived. You don't have to worry about traveling to the unit, and you gain a sense of independence and control over your treatment—something we all want for ourselves!

Talk with your health care team and see if home dialysis is an option for you!

## Charles In Charge: Lessons from the Heart

My name is Charles. I've been living with kidney disease since 1997, when I started hemodialysis. It was a little tough in the beginning to get use to, but through the years it has gotten to be a part of life.

I don't make kidney disease a burden in my life. It is only 3 days a week or 12 hours weekly. I don't do anything different! I just take my medication and watch my liquid intake and eat proper foods. I take it a day at a time.

I work 25-30 hours a week as a salesman. I represent McCormick Spices & Gravies, working for a very understanding company called Advantage Sales. The ESRD Network 4 Rehabilitation Committee recognized this company in June 2001 for their support in hiring people with End Stage Renal Disease.

Music is my hobby and an important focus of my life. I play several instruments including the clarinet, sax, and flute. I perform with the following three different organizations: The Main Street Sound Band; the Verdi Italian Concert Band and The Showman Combo.

As a matter of fact, on June 29th, 2003 my big band played a concert for both the Montgomery East unit and the East Norriton Dialysis facility. It is a big picnic held at a local park. After all we dialysis patients are one big family.



**I am living proof  
that dialysis should  
not interfere with  
work, hobby or  
pleasure**

I was selected to be a patient representative by my facility social worker, doctors & nurses, because they say I have a good outlook on life with dialysis. I speak to new dialysis patients throughout the year. I had been on the transplant list for a very long time. I was removed from the waiting list when my endocrinologist found cancer in my thyroid area. However, after treatment I am now back on the list at Lankenau Hospital.

Ah, life goes on... I'm able to take my wife to dinner; I only eat what I'm able. I have a very good idea what I can and what I can't eat. I follow the dialysis menu, pretty much and I tell all the pre-dialysis patients pretty much the same thing.

In my dialysis unit, you sort of get attached to the staff and fellow patients. When a person passes on to the Great Big Blue, he or she is missed dearly.

The one hope I have is to continue on dialysis. I am living proof that dialysis should not interfere with work, hobby or pleasure. I have all in my life. Life goes on, no matter what (with a little help from God) I enjoy every day of my life.

*This article was submitted to the Network by Charles S. Sutura of Conshohocken, PA.*

**Visit Us on the Web** <http://www.esrdnetworks.org/networks/net4/net4.htm>

ESRD Network 4, Inc. has a Web Site to serve as a resource for patients, the general public and renal professionals. Network 4 has recently improved our site. Look in the [Calendar of Events](#) for upcoming Network meetings. Check out our Annual Reports, Goals, the "Network News", and Grievance Policy. If you want to learn more about the Network, check out the [General Information](#) page.

Want to know how many patients are in a particular county in the Network? Check out the [Patient Population Report](#) found in the [Data Department](#) page. We also have a link to [The Forum of ESRD Networks](#) that provides access to the webs from the other Networks across the country. There are even links to the [Pennsylvania and Delaware Office of Vocational Rehabilitation \(OVR\)](#) web sites.

**Working for 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 you receive in your dialysis facility.

In Pennsylvania and Delaware your ESRD Network is:

### **ESRD Network 4, Inc.**

40 24th Street, Suite 410

The Crane Building

Pittsburgh, PA 15222

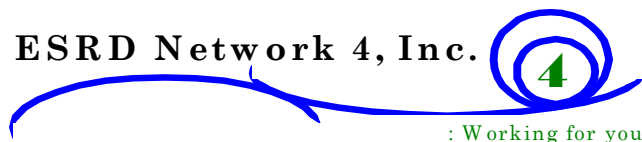
**(toll free line for patients only)**

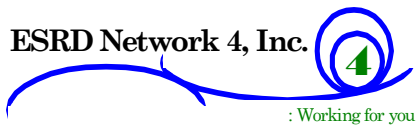
**1-800-548-9205**

Email: [info@nw4.esrd.net](mailto:info@nw4.esrd.net)

Patients and families have a right to address problems they identify in a facility, without fear of discrimination or punishment. Please use the following steps:

- Be aware of Patients rights and responsibilities, available at your facility or from the Network.
- Discuss your concern with the physician, nurse, social worker or facility administrator at your dialysis facility.
- If you feel your concern is not properly addressed at the facility level, the Network can assist by providing an impartial review of the complaint or grievance.
- All conversations regarding your complaint or grievance are confidential.
- Should you need more information about the Network complaint or grievance process, talk with your social worker or contact us directly.





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