

# Network News: For patients, families and caregivers



## Focus on Fistula

**Why are staff members asking me about my access and encouraging me to get a fistula? What is this “Fistula First” I keep hearing about?**

Vascular access is the “lifeline” for hemodialysis patients. This lifeline allows your blood to be pumped from your body, cleansed through a dialysis filter and returned to your body. The three most common types of vascular access are fistulas, grafts, and catheters. Experts agree the best access for hemodialysis is an arterio-venous (AV) fistula. An AV fistula is created when an artery and a vein are surgically joined together, usually in the forearm.

“Fistulas are the ‘gold standard’ for establishing access to a patient’s circulatory system in order to provide life-sustaining dialysis,” said Centers of Medicare & Medicaid Services (CMS) Administrator, Mark B. McClellan, MD, PhD. “They last longer, need less rework, and are associated with lower rates of infections, hospitalization and death for Medicare beneficiaries than other types of access.” For these reasons, work began on a special project in July 2003 called the National Vascular Access Improvement Initiative. This initiative is known as “Fistula First.”

## Longest Lasting Fistula Contest Winner

In our last newsletter we invited you to enter the search for the Longest Lasting Fistula in Network 4. Over 30 patients replied and from those applications here are the top four winners:

**Michael C. Hirst** had his fistula placed 1975. He receives his dialysis at FMC Dialysis Services of Cumberland, Carlisle, PA.

**Blair T. Grube** received his fistula in 1976. His unit is the Allegheny Valley Dialysis Center, Natrona Heights, PA.

**James Kizzie** had his fistula placed in 1976 and has his dialysis at DCI of Oakland, Pittsburgh, PA.

**Rosemary E. Watts** received her access in 1977. The DCI of Oakland care team members are partners in the management of her home hemodialysis.



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# What Do You Want To Know About a Fistula ?

## Questions and Answers to help you make the choice for an Arterial Venous Fistula (AVF)

**Your choice of access is critical to your care. Be sure to make the best informed choice that you can. Reach out to your health care staff today! Here are some questions to help you start.**

### 1. Question: Why should I get an Arterial Venous Fistula (AVF)?

**Answer:** It is widely accepted by the majority of Kidney Doctors (nephrologists) and other dialysis professionals that an AVF is the preferable access type by which to receive your dialysis. An AVF, with proper care, tends to be the longest lasting type of dialysis access and requires fewer interventions, such as de-clotting, which can be very painful. With an AVF, it is also likely that you will experience fewer infections, fewer days in the hospital and receive more adequate dialysis, which in turn will improve the way you feel and improve your quality of life.

### 2. Question: How do I get an AVF?

**Answer:** There are several members of your healthcare team who can provide you information about obtaining an AVF, but you might want to initiate this discussion with your physician or a nurse in the dialysis clinic. Prior to talking with your healthcare provider you would probably benefit from educating yourself about the benefits of having an AVF. Several sources of educational information regarding an AVF (some of which are included at the end of this article) are available.

### 3. Question: Who is a candidate for an AVF?

**Answer:** There are very few instances where a fistula is not indicated. Nowadays, in the majority of patients (including those with diabetes or who

are older) a “mapping” study of the blood vessels in the arm is conducted, which will help select the best veins for a fistula and decrease the chance for an unsuccessful surgery. Be persistent, if the “mapping” study was not done, asking for a second opinion is quite reasonable.

### 4. Question: I don't like needles, how do I cope with this fear?

**Answer:** There is no denying that having an AVF requires the insertion of two needles into the access site. However, there are many options for dealing with the needles. Many patients report that by learning to place their own needles, they are focusing more on the needle placement than the pain associated with the needles. Additionally, your clinic might have a topical or under the skin anesthetic available to numb the area prior to the needle sticks. There are relaxation techniques such as breathing and imagery exercises which might help reduce the anxiety often related to a fear of needles. You might also ask your clinic or MD if smaller needles might be appropriate or if other ideas for dealing with the pain exist.

### 5. Question: An AVF will change the looks of my arm, how do I cope with this?

**Answer:** The way we view our bodies is very important to the way we feel about ourselves. If you are uncomfortable with your physical appearance, it is more likely that you won't feel good about yourself in general. The repeated insertion of needles into an AVF can cause scarring and a change of appearance in your arm or wherever the AVF is placed. What is important to remember is that you have the choice to not let your feelings about

yourself be defined by the look of your access site. By opening up and talking to other dialysis patients with a fistula, you will learn the methods or coping mechanisms they have used in integrating these physical changes into their daily lives.

**6. Question: How is an AVF different from a catheter or a graft?**

**Answer:** An AVF is created by connecting (usually in your forearm) one of your own veins and arteries together, where as a graft requires the surgical placement of a small flexible tube and a catheter requires the placement of a small tube into a large vein in your neck, chest, or groin. The AVF uses your own anatomy and requires no insertion of a “foreign” substance into your body. Since an AVF uses your own vein and artery, it is less likely to clot or become infected and tends to last longer than catheters or grafts.

**7. Question: What care will my AVF require?**

**Answers:**

a. The application of pressure to the site is necessary following the end of your treatment. This will likely need to be completed by you and it will add some additional time to your time in the clinic until the access stops bleeding.

b. It will be important that you keep your access clean and wash it thoroughly prior to initiating your dialysis run. You will want to make sure anyone caring for or inserting needles into your access site is wearing clean gloves and observing infection control techniques.

c. You need to be very protective of the arm where your AVF is placed. This includes restricting others from inserting IV's, drawing blood, or taking your blood pressure. You will also want to check your access on a daily basis for any changes such as redness or swelling.

d. You might be advised not to lift any heavy objects or put pressure on your access arm because this will limit circulation.

## ACCESS RESOURCES AVAILABLE ON THE INTERNET

1. [www.ikidney.com](http://www.ikidney.com)
2. [www.aakp.org](http://www.aakp.org)
3. [www.kidneypatientnews.org/VascularAccesslinks.html](http://www.kidneypatientnews.org/VascularAccesslinks.html)
4. [kidney.niddk.nih.gov/kudiseases/pubs/vascularaccess](http://kidney.niddk.nih.gov/kudiseases/pubs/vascularaccess)
5. [www.ihl.org/IHI/Topics/ESRD/VascularAccess/Resources](http://www.ihl.org/IHI/Topics/ESRD/VascularAccess/Resources)
6. [www.esrdnetworks.org](http://www.esrdnetworks.org)
7. [www.nephron.com/judy.html](http://www.nephron.com/judy.html)
8. [www.lifeoptions.org](http://www.lifeoptions.org)
9. [www.kidneyschool.org](http://www.kidneyschool.org)
10. [www.cms.gov](http://www.cms.gov)

This is not meant to be a complete list and you can always speak with your physician, nurses, or other members of your healthcare team, or contact ESRD Network 4.

Send us an email: [info@nw4.esrd.net](mailto:info@nw4.esrd.net)



# Kidney Disease Across Generations: One Family's Perspective By Cate Lewis, RN, BSN, CNN

My name is Cate Lewis and I would like to share my story of a hereditary genetic disorder called polycystic kidney disease (PKD). I have been a volunteer for the National Kidney Foundation (NKF) since 1999 and proudly serve as the immediate past chair of the Patient and Family Council (PFC) Executive Committee.

My story began in 1972 when I was in my last year of nursing school. My dad had just been diagnosed with PKD by his family physician when probing the cause of his uncontrolled high blood pressure. An ultrasound of his kidneys revealed many large fluid-filled cysts in both kidneys. I vividly remember that not only did his doctor have little knowledge of this disease, but my medical textbook had a one-paragraph description ending with the words, "prognosis is poor".

As good fortune would have it, in 1974 there was an RN position available in a newly opened dialysis unit at the local hospital. It made sense to me to learn as much as possible about caring for people with chronic kidney disease (CKD) in order to prepare for what was potentially in store for my dad.

Later that same year I was also diagnosed with PKD. My situation followed the same scenario; dangerously elevated blood pressure readings triggered the need for an ultrasound to examine my kidneys. Another test called an intravenous pyelogram (IVP) confirmed that the diagnosis was PKD.

My biggest concern at that time, being 23 years old and engaged to be married the following May, was making the decision about having children. I have a clear picture of my kidney doctor sitting in my hospital room after

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receiving the final test results and discussing PKD with my finance and me. His advice, in response to our concerns about this disease being hereditary, was that advances would continue in not only the research of PKD but in dialysis and transplant technology. He also advised that the key elements in controlling kidney function were to keep my blood pressure and salt intake under control.

We were married May 1975 and our only child, Jay, was born in March of 1978. We were blessed with a beautiful healthy baby, but would not know until he was 18 that he had acquired PKD. Jay had a hard fall during a snowboarding jump and developed bloody urine. My hope was that this bleeding was from a bruised kidney, but my heart told me that he needed to have PKD ruled out. Ultrasound results showed that his kidneys were filled with numerous fluid filled cysts. These cysts can become infected. The cysts tend to grow slowly and are generally not visible by ultrasound until the late teen years.

My dad's kidneys failed in 1979, and he and my mom successfully performed home hemodialysis for the next four years until his death in 1983.

I continued to work in the dialysis unit and my kidney function remained normal until November 1998. At that time my creatinine (a waste product in the blood that is normally removed by the kid-

## Kidney Disease Across Generations, Continued

neys and should be less than 1.0) reached a level of 4.0, which meant I had stage 4 CKD. It was time to have an initial transplant evaluation and a vascular access created, called a fistula, for hemodialysis. It is essential to have the fistula created early, as the blood vessels need to enlarge or mature prior to use.

Having the transplant referral and workup completed before dialysis begins can sometimes eliminate the need for even starting dialysis. This may occur when a transplant candidate has a living donor when a perfect antigen match from a non-living donor becomes available.

Throughout the years I was troubled with severe pain in both cystic kidneys, episodes of cysts rupturing and bleeding and one severe kidney infection requiring hospitalization.

My kidneys failed in May 1999. Although my first choice for therapy was continuous ambulatory peritoneal dialysis (CAPD), I had the fistula created as a back-up because I knew that CAPD sometimes is not effective when people with PKD have huge kidneys due to the cysts. Too much of the abdominal space is taken up by the massive kidneys and this may interfere with the filtration of waste products through the CAPD process. I also knew that having several abdominal surgeries might eliminate CAPD from my dialysis choices because scar tissue can prevent good removal of waste products. As it turned out, I was unable to do CAPD and I began hemodialysis while waiting for a kidney transplant.

Hemodialysis worked well from May 1999 until I was blessed with a successful transplant from a non-living donor on November 18, 2001. There was, however, one major surgery that took place six months before my transplant. Although it is not

a common practice to have native kidneys removed before a transplant, it is sometimes recommended. My transplant surgeon felt strongly about the need to remove both kidneys before receiving a transplant, because the risk of infection of the enlarged kidneys after a transplant would be dangerous when the immune system would be suppressed, or basically “sleeping” because of the anti-rejection drugs. Coincidentally in 2002, I was among three people with CKD from our facility, all on waiting lists at different transplant centers, requiring kidney removal (nephrectomy).

Thirty-two years have passed since a name and face were connected to PKD for our family. I continue as a nephrology nurse at the same facility and treasure every moment of life with a gift of a kidney. My son continues to do well and has also chosen to care for people with kidney disease as a dialysis Patient Care Technician.

Technological advances continue to improve the quality of life for people facing kidney disease. Research efforts to find a cure for PKD are ongoing. An excellent way to learn about this disease as well as follow medical advances is to contact the PKD Foundation by calling 1-800-753-2873 or by visiting their Web site at [www.pkdcure.org](http://www.pkdcure.org)

Meanwhile, my best wishes to you all. Stay healthy as possible, learn as much as you can about kidney disease and enjoy life to the fullest.

Cate Lewis serves as a member of the Network 4 Organ Procurement/Transplantation Committee and Patient Advisory Committee. She is the Education Manager for patients and staff with Moses Taylor Regional Dialysis Systems and rotates through six community facilities in Scranton, Pennsylvania.

**Although my first choice for therapy was continuous ambulatory peritoneal dialysis (CAPD), I had the fistula created as a backup...**

# Safety Precautions for You: National Patient Safety Awareness

As a dialysis patient, you can take an active part in your safety with the doctor and staff at your dialysis facility. Following these safety precautions may help you function better on and off dialysis.

## Treatment Precautions:

- **Do not adjust the controls of the dialysis machine unless you are told to do so. Touching the controls will change the settings of the machine.**  
*Why: The nurse or technician sets the controls based on what the doctor orders for you.*
- **Tell the dialysis nurse or technician if you are feeling sick, dizzy, or weak.**  
*Why: This will alert the nurse or technician that you may be having a problem.*
- **If you have diabetes, watch your diet and check your blood sugars at home. Tell the nurse or technician if your blood sugars are high or low. Also, tell them if you are having vision problems, any skin color changes or sores on your body (especially of the hands and feet).**  
*Why: Early reporting will help you to limit problems caused by diabetes.*
- **Bring a copy of your discharge instructions to the dialysis unit when coming from a hospital or doctor's office.**  
*Why: The doctor and/or nurse may need to make changes to your treatment plan.*

- **Do not keep your bloodline connections covered with clothing or a blanket during dialysis.**  
*Why: The nurse or technician must be able to see your bloodlines in ensure they stay connected during treatment.*

## Access Precautions:

- **You should be shown how to take care of your access. This is usually a fistula, graft, or catheter. If the access is a fistula or graft, you should not wear tight clothing or jewelry on the access arm.**  
*Why: Pressure on the access site can decrease the blood flow through your access.*
- **Follow doctor's orders on how much weight to lift with the creation of a new access in your arm.**  
*Why: Lifting too much weight with the new access arm, before it heals, may injure the surgical area inside your access.*
- **If your access is a catheter, the skin area should be kept clean, dry, and covered.**  
*Why: This will decrease your chance of getting an access infection.*
- **Check to see that the nurse or technician is wearing gloves and a mask when working with your access.**  
*Why: To protect you from infection and to protect the nurse or technician from possible blood contamination.*

- **You should not touch the skin area or supplies when the nurse is working with the access.**  
*Why: To decrease your chance of getting an access infection.*

## Medicine, Food, and Fluid Precautions:

- **Follow a prescribed plan of taking medicine, food, and fluids.**  
*Why: Following a prescribed plan will help you to feel better on and off dialysis.*
- **You should talk with a nurse, doctor, or pharmacist before taking "over the counter" medicines or herbal remedies.**  
*Why: Some medicines can cause problems with other medicines you are already taking.*
- **Talk with the nurse or technician about what to do in case of an emergency. The nurse or technician will go over this with you.**  
*Why: Emergencies can happen at a dialysis center, home, or other places. Knowing what to do may help you during an emergency.*

## ESRD Network 4 Patient Safety BINGO



As a dialysis patient, you can take an active part in working with the doctor and staff at your dialysis facility in keeping you safe. The BINGO game board below is made up of some of the safety precautions you can take.




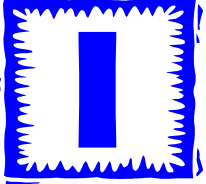


### How to play Patient Safety BINGO –

1. Write down your name and the name of your unit.
2. Place an “X” in the BINGO square if you feel you do this safety precaution or can do it today.
3. Return your BINGO card to Network 4 by March 31st, to be in a drawing to win a special prize.



My name is: \_\_\_\_\_

My dialysis unit’s name is: \_\_\_\_\_

				
<b>1</b> I have diabetes and I watch my diet.	<b>6</b> I check to see if the correct dialysis bath and artificial kidney are at my dialysis machine before starting dialysis.	<b>11</b> I take care of my dialysis access site.	<b>16</b> I bring a copy of my discharge instructions to my dialysis unit when I come from a hospital or my doctor’s office.	<b>21</b> I have diabetes and tell the nurse or technician if I have any sores on my body.
<b>2</b> I have a fistula and I do not wear tight clothing or jewelry on the access arm.	<b>7</b> I have diabetes and I take my blood sugars at home.	<b>12</b> I know why a flu shot is important to have every year.	<b>17</b> I have an emergency kit.	<b>22</b> I have a graft and I tell the nurse or technician when I notice that there is no pulse at my graft.
<b>3</b> I do NOT cover my bloodline connections with clothing or by a blanket during dialysis.	<b>8</b> I talk to my doctor, nurse, or pharmacist before taking any “Over the Counter” medicines or herbal remedies.	<b>FREE SPACE</b>	<b>18</b> I do NOT touch the skin area or supplies when the nurse is working with the access.	<b>23</b> I check to make sure the nurse or technician is wearing gloves and a mask when working with my access.
<b>4</b> I have a fistula and I tell the nurse or technician when I notice that there is no “buzz” (or thrill) at my fistula.	<b>9</b> I tell the dialysis nurse or technician if I am feeling sick, dizzy or weak.	<b>14</b> I do NOT adjust the controls of the dialysis machine unless told to do so.	<b>19</b> I have diabetes and tell the dialysis nurse or technician if my blood sugars are high or low.	<b>24</b> I have a catheter and I keep the skin area of the catheter clean, dry and covered.
<b>5</b> I have diabetes and tell the nurse or technician if I have any skin color changes.	<b>10</b> I let my nurse and social worker know where I am going at least six weeks before I travel.	<b>15</b> I know how to take myself off dialysis in the event of an emergency.	<b>20</b> I have a back-up plan for a ride to get me to and from my dialysis center.	<b>25</b> I have diabetes and tell the nurse or technician if I am having any vision problems.

# Bridges to Rehabilitation

About every 12 minutes, more than 100 times a day, someone in the United States is told he or she has Chronic Kidney Disease (CKD). Many of these individuals feel this will mean the end stage of their lives. A few may even allow the illness to destroy their hopes and dreams.

How much will it, or has it changed your life? A lot depends on you.

It is up to you how much you want to keep your life the way it has been or make changes to improve your situation. There are many people who can help, provide good sources of advice and help you with rehabilitation.

**Rehabilitation** means restoring you to stable health, a positive outlook, and activities you enjoy. Changes in medicine and treatment have made dialysis treatment for CKD more effective. This means that now more than ever before, kidney patients have the potential to return to an active and productive life. Rehabilitation for kidney patients means a coordinated program of:



These pieces of rehabilitation all work together and can improve your fitness and energy, increase your ability to work, and help you have a better life.

Setting goals for yourself is important and can include:

- ◆ A good understanding of your treatment and taking part in planning
- ◆ Better fitness, getting back to activities you enjoy
- ◆ Education
- ◆ Employment

## Myths and Obstacles

The myths range from “dialysis patients are too sick and unstable to work” or “people with CKD who are working or who have had a transplant don’t need and aren’t eligible for vocational rehabilitation services”. The fact is that people on dialysis, or who have had successful transplants, are extending their life expectancy by years.

The clear message is that people with CKD are fully able to participate in the workforce.

If you are new to dialysis you may not know what to expect. If you have been on dialysis for a while, you may wish that you had been given these options a lot earlier. Learning about this early may help you know what to do to overcome obstacles to rehabilitation.

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## Bridges to Rehabilitation, continued

*(Continued from page 9)*

First and foremost, you are the key member of the treatment team. It is up to you to be active, motivated, and verbal. Your treatment team includes you, your nephrologist, nurses, social worker, dietitian, dialysis technician and your family. The staff members on your team are good resources for you. It is good to know what options are available.

To assist patients in living better lives, the Life Options Rehabilitation Advisory Council identified the following five “bridges” or five “E’s”:

**E**ncouragement – working hard for something and taking control of your life gives you a sense of purpose.

**E**ducation – the more you learn about your illness and its treatment, the better you will manage it.

**E**xercise – regular exercise can improve your fitness, give you more energy, and make your general health and outlook better.

**E**mployment – if possible, don’t quit your job; a job gives self esteem, identity, independence, a sense of accomplishment, a social outlet and a higher standard of living.

**E**valuation – research is being done across the country on ways to support rehabilitation; you too can evaluate what the barriers to rehabilitation are.

**To learn more about the possible options for rehabilitation, returning to work or continuing education, speak to your social worker or contact the Office of Vocational Rehabilitation.**

**In Pennsylvania call 1-800-762-4223 and in Delaware 1 302-761-8275.**

## Medicare Has Information on Quality of Care and Resources For You

If you need to locate a dialysis clinic, whether for chronic care or for travel, an important tool is available to help you in your search. **MEDICARE** has quality of care information on all Medicare-certified dialysis facilities so you can make an informed decision. You can also learn about important kidney disease resources. Research and compare dialysis facilities in your area by visiting [Dialysis Facility Compare](#) on the Internet at [www.medicare.gov](http://www.medicare.gov)

If you need assistance in understanding the Dialysis Facility Compare website, ask your dialysis staff or call ESRD Network 4 at [1-800-548-9205](tel:1-800-548-9205).

## AM I NORMAL? The Fifth in a Series About Kidney Disease

By Eileen Zerbe, MSW, from BMA of Christiana, Newark, DE

This is the final article in a series exploring some of the feelings and experiences of persons living with Chronic Kidney Disease and on Dialysis. The first four 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 patients and members of their families. The first four articles discussed denial, anger, depression and sexual difficulties as common reactions to a chronic illness. This last article of the series explores acceptance of one's own renal failure.

Acceptance of renal failure does not necessarily mean being happy about being on dialysis. We could probably ask any dialysis patient how they felt about being on dialysis and they would say they would rather be any where but sitting in that dialysis chair for four hours. On the other hand, people who are able to accept their condition also no longer have negative feelings about their illness. They have been able to get beyond their anger and reach the point where they realize that renal failure and dialysis are only part of their life, not their total life.

Acceptance of renal failure is an attitude and a refocusing of one's life. It is a matter of seeing the glass as half full instead of half empty. In the beginning, renal failure and dialysis seem to take over your life and it seems you can't see or think of anything else. Acceptance is when you

**...you are not alone and many other dialysis patients feel and experience many of the same things you're going through.**

have made the often difficult but necessary changes to your life caused by renal failure and then realize that dialysis is only a part of your life. There are still 156 other hours in the week to do what you want to do. There is time to have a life, resume your career or favorite hobby or take up anew one.

Some people are able to accept their condition in a relatively short period of time. Most struggle for months or years. Others never are able to get through feelings of denial, anger and depression. It is hoped that these articles have helped you better accept your chronic kidney disease and dialysis. Hopefully, they have also helped you realize that you are not alone and that many other dialysis patients feel and experience many of the same things you're going through. YOU ARE NORMAL! Talking about what you are going through, trying to remain active and involved and seeking professional help if you need it are all positive ways to help you regain control of your life rather than having your disease control you.

## Saying Thanks

Are you working, or know someone on dialysis who is? Would you like to say "Thank you" to the boss for anything? Maybe your boss made special accommodations for you, or you're just grateful for the job. Let your gratitude be known! Details are coming soon to your dialysis unit, and our website, on how you can nominate an employer for a special award of recognition.

<http://www.esrdnetworks.org/networks/net4/net4.htm>

**Working for you**

## **ESRD Network 4 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; ESRD Network 4, Inc is working for you.**

### **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**

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 dialysis 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 how the Network complaint or grievance process works, talk with your social worker, see the Network bulletin board or call us directly.

