

Spring 2007

ESRD Network 4, Inc.
is working for you!

Network 4 News

*A Newsletter for People with Chronic Kidney Disease
and their Families in Pennsylvania and Delaware*



Western PA Kidney Kamp (WPAKK)

The **Western PA Kidney Kamp** was founded in 1995 as a weeklong camp experience during the first week in August for children suffering from kidney disease. Children between the ages of 6 and 18 who have had a kidney transplant as well as those on peritoneal dialysis and hemodialysis are welcome to be a part of the camp. Peritoneal dialysis is available on site while hemodialysis is provided at a nearby outpatient dialysis facility. Most important, the camp provides the families with a break

from the emotional and physical strain of dealing with a chronic illness while offering the children a week of fun and companionship with others sharing the same diseases.

The camp is located on the grounds of the Ligonier Camp and Conference Center just a few miles north of the beautiful town of Ligonier in the Laurel Highlands area of south western PA. The LCCC offers several activities for the campers as well as a trained resident staff. The onsite activities

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- Do you like rock wall climbing (like this this guy)?
- Do you like archery, swimming, field hockey or basketball?
- Are you 6 to 18 years old?
- What are you doing this summer?

Consider going to
Kidney Kamp!

Getting to Know Fistulas

As most of you know, Network 4 is currently participating in the national Fistula First initiative. The goal of Fistula First is to increase the number of people using a fistula in the United States to a rate of 66% by 2009. The current Network 4 fistula rate is at 44.2%, with the national rate at 45.2%. This means we still have a lot of work to do to meet our national goal.

provide life-sustaining dialysis. They last longer, need less surgical revisions, and are associated with lower rates of infections, hospitalizations, and death.” [Quote by Centers for Medicare & Medicaid Services (CMS) Administrator Mark B. McLellan, MD, PhD]

Should I have a Fistula?

Another reason to consider a fistula is that it usually last for years, and has fewer problems with clotting compared to other access types, such as a catheter or a synthetic graft. A fistula can usually deliver a better blood flow which results in a better treatment.

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Why all the attention regarding a fistula?

"Fistulas are the 'gold standard' for establishing access to a patient's circulation in order to

My Fistula Story - Patient Perspectives



Elizabeth Churilla

I have been a dialysis patient for the past 17 years. I am currently dialyzing in the DaVita of Pittsburgh facility. I have never had a kidney transplant. My kidney problems started at the age of 16 due to a medical problem I had been diagnosed with shortly after birth, where my bladder never matured. The doctors said that I would need to have dialysis sometime in the future. I had my first fistula placed 8 years before I started dialysis because the doctors thought I would need to have dialysis much earlier in my life. I really was in denial for many years about having kidney failure and probably could have started dialysis much sooner than I did. Finally, at age 40, I started dialysis.

The fistula lasted for 5 years, and I learned how to put in my own needles. After losing my fistula, I had an AV graft placed in my right arm and it lasted for 4 years. After the 1st graft failed, I had 2nd graft placed in my left arm that lasted 3 years. After the 2nd graft failed, I had 2 different permanent catheters placed that lasted a total of 4 years. After the catheter became infected, I had a graft placed in my left thigh and that is what I am currently using. I have learned to put the needles in myself. Although I no longer have a fistula, the different accesses have convinced me of the advantages to having a fistula, such as a lower infection rate, less restriction from activities & less difficulty with the insertion of needles.

The advice I would offer to people who are diagnosed with kidney disease and having to go on dialysis, would be *“to have a fistula placed as early as possible.”* This way they have a ready access for dialysis when the time comes.

(Written, edited & printed with permission from Elizabeth Churilla, who receives her dialysis care from DaVita of Pittsburgh, PA) ☀



Marlys Penwell

I am a 71-year-old female patient who has been on hemodialysis since April of 2006. I have a fistula that was placed about 5 years ago because the doctors thought I would have to have dialysis soon after my diagnosis of kidney disease. I feel fortunate that I did not have to start dialysis treatment until 4 years later. A kidney biopsy showed my kidney disease was from high blood pressure and adult type II diabetes, controlled with diet.

My fistula works wonderfully, and except for the initial pinch when putting the needles in, I have no other discomfort of my fistula. I really don't have any “body image” issues with the fistula's appearance, and am very appreciative that dialysis is available for me. I stay active and have wonderful family support when it comes to dealing with this illness and dialysis. The fistula really has not hampered my activities of daily living. I watch my grandchildren, visit with my mother at the nursing home, and talk with other patients who might be having problems adjusting to the illness and dialysis.

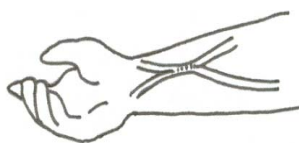
My advice to other people who are diagnosed with kidney disease that have to be on dialysis, is to keep a good attitude, keep up your faith and stay involved in something that makes you feel good.

(Written, edited & printed with permission from Marlys Penwell, who receives her dialysis care from DaVita of Homestead, PA) ☀

Getting to Know Fistulas (continued from Page 1)

What Does It Look Like?

An arterio-venous fistula (AVF)



is created by sewing together the person's own artery and vein underneath the skin. The pressure from the artery causes the vein to enlarge, making needle insertion simple. This helps to create easy "access" to your bloodstream.

How do I get an AVF?

The AVF access is created by a vascular surgeon who is familiar with dialysis patients. This procedure takes place in the hospital out-patient surgery department or a Vascular Access Center. During the procedure, most patients are awake and mildly sedated. As with any minor surgery, you may be prescribed a mild pain-reliever for a few days. 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.

Who is a candidate for an AVF?

There are very few instances where a fistula is not

indicated. Diabetic or elderly patients may need some additional testing before access surgery is considered. With most patients, a "mapping" study of the blood vessels in the arm is conducted, which will help your surgeon select the best veins to insure a successful fistula. Be persistent; if a mapping study was not done, asking for a second opinion is quite reasonable.

I don't like needles, how do I cope with this fear?

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 type of anesthetic available to numb the area prior to the needle insertions. There are relaxation techniques such as breathing and imagery exercises, which might help reduce the anxiety often related to a fear of needles. Your social worker may be able to offer suggestions. You can also ask your doctor

if smaller needles might be appropriate or if other ideas for dealing with the pain exist.

What additional care will my AVF require?

At the end of your treatment, you will need to apply pressure over your needle sites for about 10 minutes, or until the bleeding has stopped. It is very important that you keep your access clean, and you may even be asked to clean your fistula arm prior to dialysis. You will want to make sure anyone caring for or inserting needles into your access site is wearing clean gloves. Since most fistula are placed in the arm, you need to protect that arm from injury. This includes restricting others from inserting IV's, drawing blood, or taking your blood pressure from your access arm. You will also want to check your access daily for any changes such as redness or swelling, a decrease in the blood flow or the absence of a "buzzing" sensation. Any changes need reported immediately to your dialysis staff. It is also recommended to avoid lifting heavy objects or placing pressure on your access arm (carrying heavy books, boxes, etc.) because this will limit circulation.

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Fistula First (continued from page 3)

Believe it or not, deciding to get a fistula placed could be compared to trying to quit smoking! They are both 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 wonder, "What is my arm going to look like after this?" Other patients have a fear of having needle sticks. Some patients have questions about the surgery. If these are some of your concerns, find out what other patients are feeling and talk to your health care team. ☀

Western PA Kidney Kamp (continued from page 1)

offered include trust building initiative games; two challenging low ropes courses; a fifty foot, four sided climbing wall designed for climbers of all abilities; and a one thousand foot zip line for older campers. Campers can also enjoy archery, swimming, field hockey, basketball, a fun filled day at a local amusement park and possibly a field trip to a museum or other interesting locations. There are always plenty of craft projects on hand and even help from the local Home Depot.

The camp is operated solely through donations. Dialysis Clinic, Inc., a not-for-profit corporation, is the main sponsor for the camp but generous contributions from the National Kidney Foundation (NKF), American Nephrology Nurses' Association (ANNA), the Renal Round Table and many others help make the camp experience possible. Some groups choose to sponsor various events or activities. The local ANNA Chapter

sponsors a themed party evening that is always a camp highlight, and DCI Monroeville sponsors the refreshments, games and gift bags for the opening night pool party. Camper's families are asked to donate what they can afford. If they cannot afford to make a donation, the families are asked to complete a grant application for AKF (American Kidney Foundation) assistance. One hundred percent of the donations received fund camper events or activities and are never used for administrative expenses or salaries.

Accommodations at the LCCC Lamont Lodge are a little homier than the visions one would have when thinking of a camp. The campers share dorm type rooms usually in groups of four. Most meals are prepared by camp cooks and served in a cafeteria type setting. Specialized menus are available to meet the individual nutritional needs of any camper. But the real meal highlights are the campfire meals prepared by the campers themselves. The smell of fresh

locally grown corn boiling and hot dogs roasting holds the attention of all hungry campers. Many campers have their first experience with making smores and mountain pies at WPAKK.

Driven by the hard work of dedicated people, the camp is a spirit lifting experience to many who dedicate their careers to working in the dialysis field. It's a 'feel good' reminder that we can all make a difference in someone's life. The camp not only offers a one-week experience but it creates lifelong friendships for many who attend. Many who first came as campers are now junior counselors and share their time and experiences with the new comers.

If you are interested or know someone who may be interested in becoming a part of our camp family, please contact: Bob Kraynik *or* Amy Dziobak at Dialysis Clinic, Inc 722 Fourth Ave. New Kensington, PA 15068 *Phone:* 724-339-1772 robert.kraynik@dciinc.org amy.dziobak@dciinc.org ☀

Knowing Your Numbers! (Part 1: Maintaining Healthy Bones)

Did you know that Network 4 has a committee of patients who offer the Network advice and comments on patient projects?

Did you know that these committee members are either on dialysis or have received a kidney transplant?

Did you know that this committee, the Patient Advisory Committee (PAC), is concerned that some patients may not fully understand the importance of lab numbers?


Do you *Know Your Numbers*, and how they affect your health?

With recommendations from the PAC, the Network will focus on providing a series of educational newsletter articles devoted to “Knowing Your Numbers”. In this article, the focus will be: **Maintaining Healthy Bones through Phosphorous and Calcium Control.**

When your kidneys were healthy, they protected your bones. Healthy kidneys help to keep the proper amount of calcium and phosphorous in your blood. Healthy bones need a balance of both calcium and phosphorous. When kidneys do not work, they do not remove the extra phosphorous from the bloodstream, and the level of phosphorous in the blood becomes too high. This tips

the balance, causing the calcium in the blood to become too low. Your body then tries to balance the calcium level by “pulling” the calcium from your bones, making them weak.

Look on your Lab Report every month



The normal range for Phosphorous is between 3.5 and 5.5

The normal range for Calcium is between 8.5 and 9.5

Are Your Numbers in these ranges?

Problems of *high phosphorous* include:

- itchy skin
- red eyes
- bone & joint pain

More serious problems can also cause:

- buildup of mineral deposits in your kidneys, heart, blood vessels, lungs, eyes, joints & skin
- bone disease
- heart disease

Low phosphorous levels are rare, and can be caused by not eating enough or taking too many phosphorous binders.

Signs of *low phosphorous* include:

- poor appetite
- confusion

How do I control my phosphorous level? Is Diet important?

Most foods contain phosphorous, but some foods contain higher amounts of phosphorous such as:

- milk, cheese, ice cream, pudding, and custard
- dried beans and nuts
- wheat and bran products
- dark cola drinks, beer
- chocolate

Together with your dietitian you can create low phosphorous meals that are both tasty and nutritious. Your dietitian can also help you with making healthy choices when you are grocery shopping, cooking, or going to restaurants.

How do medications help?

Phosphorous binders, taken with meals, act as a magnet to pull phosphorous out of your food before it gets into your blood. Discuss with your doctor and your dialysis team about your dose and how often to take the binders. When dining out, keeping a supply of phosphorous binders in your purse, pocket or vehicle can help you to keep on course with phosphorous control.

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Know Your Numbers (continued from Page 5)

How do I manage my calcium level?

It is important to understand that calcium control is similar to phosphorous control. Almost all calcium comes from the food you eat, especially from milk and other dairy products. Because these foods are limited in your renal diet, it may be necessary to take calcium supplements. Your dialysis nurse, dietitian or doctor will discuss which supplements are best for you.

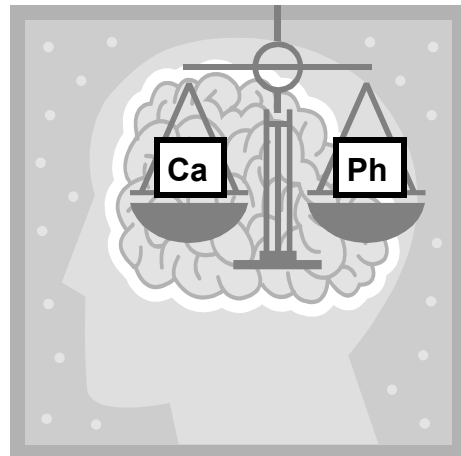
*Signs to look for with **low calcium** include:*

- Cramping, muscle twitching or seizures
- Tingling fingers
- Depression

*Signs of **high calcium** include:*

- Weak muscles
- Tiredness
- Cramps
- Confusion

Paying attention to your dialysis, diet, phosphorous binders, calcium supplements and **Your Numbers** (lab values), will help you achieve and maintain healthier bones.



It may take a little effort on your part, but with healthier bones you may have a more active lifestyle. You should be able to continue your activities, enjoy your hobbies, spend more time with your family and friends, and perhaps return to work. ☀

Renal Friendly Recipe

FESTIVE PINEAPPLE CHEESE BALL

Portions: 26 *Serving Size:* 2 Tablespoons

Ingredients:

- 3 - 8 oz. pkgs cream cheese, softened (substitute with low fat cream cheese if desired)
- 1 - 20 oz. can crushed pineapple, well drained
- 1/2 cup chopped green bell pepper
- 1/2 tsp. garlic powder

Preparation:

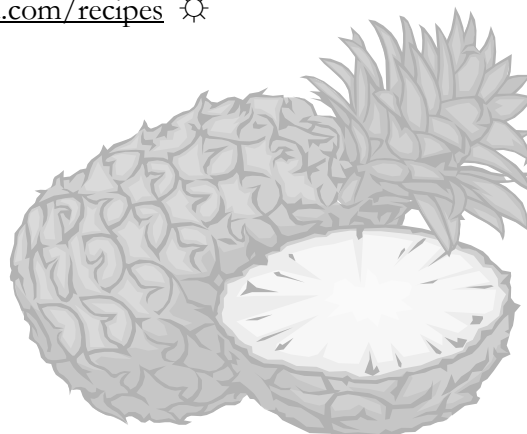
1. Place softened cream cheese in large mixing bowl
2. Add remaining ingredients & mix well to blend
3. Shape mixture into ball. Wrap in wax paper & chill overnight

***Serve with a variety of crackers or chips**

Calories: 95, **Protein:** 2g, **Fat:** 9g, **Cholesterol:** 26mg, **Sodium:** 80mg, **Potassium:** 39mg, **Phosphorous:** 19mg, **Calcium:** 2mg, **Fiber:** 0.1 g

Renal & Diabetic Food Choices: 1/2 milk, 1 Fat

This & other renal recipes can be found at:
www.davita.com/recipes ☀



My Fistula Story - Patient Perspectives



Lawrence Drenswick

I walked into the hospital late one night in February of 1990 with advanced kidney failure. A subclavian catheter was inserted to permit immediate dialysis, with an A/V fistula placed in my left forearm a day or so later. My first dialysis was on Valentine's Day.

A few weeks later, my catheter insertion site became infected, for which I needed to be hospitalized and the catheter removed. I was forced to use the immature fistula for dialysis, which fortunately worked. Dialysis continued for almost five years.

I received a successful transplant in late December 1994, which lasted for about 10 ½ years. During that time, surgeons recommended that I have the fistula removed. With the philosophy that "you never know", I didn't. Consequently, this fistula serves well, now that I am back on dialysis.

As far as care of the fistula is concerned, I visually examine, and feel for pulse and flow many times daily. I keep it clean and protected, and do not wear constrictive clothing. The fistula has not negatively impacted my daily activities in any way. However, I chose to give up archery, since possible harm could result from an accidental bow-string injury. Preserving my fistula far outweighs my enjoyment of archery. Besides that, my brother wanted the bow.

(Written, edited & printed with permission from Lawrence Drenswick, who receives his dialysis care from FMC Hermitage, PA) ☀



Poetry Corner

My fistula's name is HOPE, exclusively to me,
It reminds me of my daily health you see.
I had some difficulty with my first fistula friend,
Because it only lasted a short timely end.
My arterial and venous veins did not mature,
As a result I had multiple bleeds galore.
But now my revised fistula is functioning great,
Doing all it should-HOPE fistula, my mate.
I write to tell you that I'm doing well,
My revised fistula is performing consistently,
Oh, so well.
My treatment with HOPE fistula has no pain,
So I continue dialysis with positive aim.
With super stoppers I don't have any bleeds,
I feel very confident-I'm very pleased.
So patients on dialysis-here is the trick,
Be kind to your fistula-a personal fix .

(Written, edited & printed with permission from Sandra Tokar, who receives her dialysis care from DaVita Jefferson Dialysis, PA) ☀

Fluid Tips for Summer

- Rinse mouth out with ice water
- Freeze grapes or blueberries and snack on them
- Put lemonade, grape or cranberry juice in ice cube trays & freeze.
remember ... 1 cup ice = ½ cup fluid
- Add a lemon or lime slice to cup of ice or suck on a chilled slice of either ... gives you pucker power
remember that summer fruits and vegetables do contain some fluid, about ¼ to ½ cup per ½ cup serving

(Provided by: Dorothy Havens, RD, Renal Dietitian, Delaware) ☀

Be Safe! Be Prepared!



While nobody likes to think about being involved in an emergency situation, it is important in the light of the major disasters of recent years to know how to prepare for and act in one, especially if you are a dialysis patient. Most emergencies are minor and pass without incident (such as a brief power outage), but as a dialysis patient it could be life saving to know what to do in an emergency lasting long enough to affect your health.

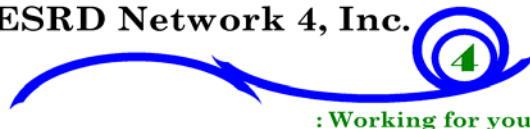
The following tips are just a few of the precautionary measures you should do in order to prepare for an emergency or a life-threatening situation. ESRD Network 4 has a full Emergency Preparedness Resource for Dialysis Patients that was made possible by a grant from Amgen®. This manual can be obtained by calling the Network at 1-800-548-9205, or by visiting our website under the section called "Patient Resources".

EMERGENCY TIPS

- √ Provide your dialysis unit with current telephone numbers, remain at home and wait for the dialysis unit to contact you.
- √ Maintain a **week's** worth of your current medications at all times and instructions for administration.
- √ Remain at home, but if you must seek shelter, take your week's worth of medication, emergency supplies, personal items, blanket and Medic Alert ID information.
- √ Know how to care for your access.
- √ Know your dietary guidelines for emergency preparedness and maintain appropriate dietary supplies. ☀

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