



KIDNEY CONCERNS

FALL/OCTOBER 1998

ISSUE 26

Three New PAC Members



David E. Broach

I contracted a strep infection as a small child that led to acute nephritis. At the time there weren't many treatment options and I've been told that my condition was grim. My parents had read of an experimental treatment involving exposing the patient to measles.

As strange as it seemed they decided to give it a try. Against all hospital rules, they put me in bed with a child with measles, and I contracted the disease. It apparently worked. My kidneys regained some function, but I was left with chronic nephritis.

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Carolyn Davis

I have been a peritoneal dialysis patient for a little over four years. I am 34 years old, just recently married this past August, and I am the mother of a 7 year old son.

I have been employed full-time for the Oklahoma Tax Commission for 7 years. In the last four years, I have been through hemodialysis, 2 transplants, 4 nephrologists, 3 dialysis clinics, and I feel like I've been through every possible pitfall a renal patient could experience in such a short length of time. But through the grace of God and a wonder-

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Carl & Kathleen Nettleton

It has been a long time since I have thought about my history as a kidney patient. It all began in the summer of 1973. I had been to a Fourth of July picnic and had a great time. The next day I woke up swollen from head to toe. My parents took me to a local hospital where I was diagnosed with acute nephritis (Bright's Disease).

With this diagnosis I was admitted to a regional hospital where I was kept for 6 solid months. I was dialyzed temporarily, but was discharged with

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"Glad You Asked That . . ."

QUESTION: *Why are two people of different size dialyzed for the same amount of time?*

ANSWER: There is no simple answer to this question. There are lots of factors that go into the decision by the medical staff as to how long a patient must dialyze to get an acceptable amount of dialysis.

One answer of many to this question is that it depends on the clearance of the Blood Urea Nitrogen concentration (BUN) or "how well the treatment is cleaning your waste from the blood."

One way to report this on your lab results is a measurement called Kt/V (pronounced K T OVER V). The "K" stands for the urea clearance in milliliters per minute. The "t" is the dialysis time in minutes. The "V" is the volume of distribution of urea in the body. The number

you want on your lab is at least a 1.2.

There are many factors that have an impact on the amount of time you dialyze and your Kt/V results. These include the size of the dialyzer that provides the space for the blood cleaning.

One factor is the blood flow rate to the dialyzer, which should be set at the rate the doctor has chosen. Another factor is the rate at which the dialysate, or blood cleaning fluid, is sent through the dialyzer.

The common things that can impact the time spent on dialysis are how well your access is functioning, how well you follow your diet and fluid intake. If your access is not functioning or is clotting, it will decrease the blood flow ability.

If you do not follow your diet you are producing more waste that will need to be dialyzed. If you put on too much fluid, a portion of your dialysis time will be spent removing fluid instead of cleaning the blood.

As you can see, the answer to this question is not a simple one. It is dependent on a number of factors and is as unique as the individual.

If you have any questions for "Glad You Asked That," forward them to ESRD Network 13, 6600 N. Meridian, Suite 155, Oklahoma City, OK 73116-1421, or phone 1-800-472-8664. Selected questions will appear in future issues of *Kidney Concerns*.

Your Doctor and You

At no time in a patient's life is it more important to have a physician that you can communicate with easily than when you have a chronic disease such as ESRD. Here are some tips on how to form a good partnership:

1. Choose a physician with a practice style you are comfortable with. It's not always important that you like your physician, but you must be able to trust the decisions made about your care. Does your doctor take time to explain aspects of your care with you and your family? Does the physician make

referrals for your other needs like social worker or dietitian?

2. Consider the nature of the practice. Does the physician work alone or with a group of doctors? Can a doctor be easily reached if an emergency occurs? Also, consider the office accommodations and staff. Are you able to get appointments easily? Are you comfortable with the office staff and are they helpful to you?

3. Be informed about your illness. If you don't know where to look, your physician's office should have information regarding kidney disease and the different forms of treatment. Know about all your

options before choosing what treatment is best for you. You can be a part of the decision process for the short/long-term goals of your healthcare. Let your doctor know how you view your illness. Prepare a living will and keep a copy with your doctor and family so that they know your wishes should your condition become grave.

4. Prepare for visits to your physician. Play an active role in your medical care. Learn what symptoms to look for and note for your physician.

Your relationship with your phy-

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Continued - David Broach

Although my parents were thrilled at my recovery, they were told that my kidneys would likely fail by adolescence or early adulthood. At the time, of course, this was a death sentence as dialysis, much less transplantation, wasn't to be developed for a number of years. In 1990, nearly forty years later, my kidneys finally gave up the ghost. By then dialysis had not only been developed but vastly improved, and transplantation was routine.

A few years earlier, my sister had joked that if I ever needed a transplant I could have her kidney. When the time came, she graciously renewed her offer without being asked. We were tested, and we matched. After only a few weeks on dialysis, I went to San Francisco, where she lived, and received my transplant. The procedure went perfectly, and we were both out of the hospital in less than a week.

Since then I've had no real problems resulting from the transplant or the medications. I've been very fortunate. My kidneys waited for technology to catch up before they failed. My sister didn't even flinch when the time came, and my surgery and recovery went perfectly.

My good fortune is precisely why I am delighted to sit on the ESRD Network 13 PAC. I've found that my involvement as a Trustee of the AKF has given me the opportunity to be of some help to ESRD patients. I believe that my involvement with the PAC will expand those opportunities.

Continued - Carolyn Davis
ful healthcare team, I feel I have finally found peace with myself and my illness.

My first experience with Network 13 was at a seminar that was held in Tulsa this past year. It was such a positive experience for me and my husband. The staff was so nice and helpful. It actually turned out to be educational and fun.

I learned there is life after renal failure. I learned that although everyone has their own coping measures, the important factor is finding the one that works for you.

I am very pleased to be a member of the PAC, and I hope to be as beneficial to the Network as they have been for me.

Continued - Carl Nettleton
only medications and a low sodium diet. I was then monitored on a monthly basis.

My catheter for CAPD was placed in 1981. During this time I was attending college. I also began working full time at Ochsner Medical Institution in the computer department. This catheter lasted for 12 years with only 2 incidents of peritonitis.

The first incident of peritonitis was contracted in Mexico during a vacation. The second occurred in the summer of 1993 and did in my peritoneum, which ended my ability to do CAPD.

In the summer of 1993 I had a graft placed in my arm in preparation for hemodialysis. At the same time, the discussion was brought up of my having a transplant. I had met earlier with a transplant surgeon, who recommended that I wait for technology to catch up with me. Well, this was the time to try.

My parents immediately decided to get tested for possible matching, and my mother was a good 3-point match. So, on November 11, 1993, I received a kidney from my mother.

Things started on shaky ground. Within the first few months, I had been in the hospital with acute rejection. This was not what I had envisioned with a Living Related Donor (LRD) kidney. I experienced difficulties with anti-rejection drugs with led to eventual chronic rejection of the kidney.

In November 1996, I underwent a nephrectomy in which the transplanted kidney was removed. I am now back on hemodialysis. I am also once again on the list for a kidney transplant.

I was married in August 1995. I completed my B.A. in Secondary Education from the University of New Orleans in 1996.

I am glad to have the opportunity to serve on the ESRD Network 13 PAC. I believe that my experience in the areas of hemodialysis, peritoneal dialysis and transplantation give me a unique insight that will be beneficial to all patients.

Continued - Your Doctor and You
sician is fundamental to your care because that person will remain constant over the course of your illness. It is essential that you be able to express your needs, state your preferences and obtain information you require to make informed decisions. By forming a partnership with your physician, you can assure that these goals are met.

STAY HEALTHY AND ACTIVE. . .

GET YOUR FLU SHOT THIS YEAR!

THERE ARE
TWO THINGS YOU
WON'T GET FROM
A FLU SHOT . . .



I. THE FLU

Flu shots use an inactive virus. You can't get the flu from a flu shot.



II. THE BILL

Medicare pays for your flu shot.

Note: people who are allergic to eggs should consult their health-care provider before getting a flu shot.



- **Do I need a flu shot every year?**

Yes, because the flu virus changes every year.

- **How serious is the flu?**

The flu is ALWAYS serious for people over 65 and the chronically ill. It can lead to dangerous - and costly - health problems.

- **When should I get my flu shot?**

The best time is in the fall, before flu season starts. By getting your shot, you'll also avoid spreading the flu to loved ones.

Remember, Medicare, Part B, pays for the shot, no matter where you get it. As long as the person giving the shot charges no more than Medicare pays, your shot will cost you nothing. HMO members must get their flu shots from their HMO.

Be sure to ask whether it's time for a pneumonia shot, too.

Pneumococcal Vaccine (PPV)

Who should get PPV?

- All Adults 65 or older
- Anyone over 2 who has a long-term health problem such as:
 - Heart Disease
 - Lung Disease
 - Sickle Cell Disease
 - Diabetes
 - Alcoholism
 - Cirrhosis
 - Leaks of cerebrospinal fluid
- Anyone over 2 who is taking any drug or treatment that lowers the body's resistance to infection, such as:
 - Long-Term Steroids
 - Certain Cancer Drugs
 - Radiation Therapy
- Alaskan Natives and certain Native American Populations

- People in need of a second dose. Ask your physician whether you are in need of taking the PPV again.

How can I learn more?

- Ask your doctor or nurse. They can give you the vaccine package insert or suggest other sources of information.
- Call your local or state health department
- Contact the Centers for Disease Control and Prevention (CDC):
 - Call 800-232-7468 (English)
 - Call 800-232-0233 (Spanish)
 or visit the CDC National Immunization Program website at www.cdc.gov/nip



KIDNEY KONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for WINTER/JANUARY. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

Kidney Concerns
% ESRD Network 13
6600 N. Meridian Suite 155
Oklahoma City, OK 73116-1421
1-800-472-8664

This newsletter is developed while under contract with the Health Care Financing Administration, Baltimore, Maryland. HCFA Contract #500-97-E031.