



KIDNEY CONCERNS

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With a Little Help From My Friends

Billy Kolb, a hemodialysis patient from Cache, Oklahoma, had a special person come into his life in December 1997. Her name is Carolyn Merritt.

Billy was diagnosed with End Stage Renal Disease in early 1996 after a life long struggle with diabetes. He met Mrs. Merritt when her husband began dialysis treatment at the same facility as Billy.

Mrs. Merritt found out in February 1998 that Billy was on the transplant waiting list and decided that she wanted to help him obtain his goal of receiving a pancreas/kidney transplant. She became chairperson of the Billy Kolb Transplant Fund.

The obstacle faced by Billy and most persons waiting for a non-kidney transplant is the funds needed for the operation. Mrs. Merritt got things started by donating the proceeds from the sale of some stamps from her stamp collection. Since that time she and Billy have been active in other fund raising activities; cookbook sales, car washes, benefit dances, bake sales, garage sales and a stop-light fund-raiser.

Additional activities have been a concession booth at several events in Medicine Park, Rush Springs and the Easter Pageant at Holy City in the Washita Mountains.

Organ Transplant cookbooks and t-shirts along with food were sold at these events. An auction was held at the Carnegie Fairgrounds in April 1998 that raised

additional funds. Many people in the Carnegie and the surrounding communities donated items and attended the auction. Bill Russ of Antlers, OK donated auctioneering services. Locally renowned artist, Ric

Hamilton, has donated a limited number of signed prints of the *Kiowa Sharpshooter* towards assisting in the fund raising for Billy.

The Organ Transplant Fund, Inc. has also been active in fund-raising with Billy. At last check, they were lacking just under

\$4,000 to reach their goal.

When asked about why she has gotten involved in this cause, Mrs. Merritt replied, "Just knowing that such a conscientious, young man with many productive years left was lacking only money, I knew I must help. It helps me to know that there is someone who knows what my husband is go-

ing through. I have my health so I felt moved to help someone who does not and bring the issue of kidney disease beyond the medical community."

Mrs. Merritt continues to approach both the private and public

sector in reaching the goal set for Billy to pay for his transplant. Billy remains on standby for his transplant operation while he waits for a donor. In the meantime he'll get by with a little help from his friends.



Carolyn Merritt & Billy Kolb

"Glad You Asked That . . ."

QUESTION: *What is hypertension and why do I need to control it?*

ANSWER: High Blood Pressure, referred to as hypertension, is the second leading cause of End Stage Renal Disease (ESRD). High blood pressure simply is the increased tension or pressure in the arteries.

There are two types of high blood pressure: Essential Hypertension and Secondary Hypertension. Presently, medical science does not know the cause of Essential Hypertension. Genetic predisposition may be a cause. Secondary Hypertension has been linked to organic defects, such as kidney disorder and Atherosclerosis, or hardening of the arteries from plaque buildup.

Uncontrolled high blood pressure damages the blood vessels in the kidneys, Renovascular Hypertension, which interferes with their ability to filter waste from the blood stream and lowers the blood pressure to the kidney. The kidney responds by releasing hormones that raise blood pressure causing more fluid pressure. This fluid build up causes increased pressure on the vascular system and heart and can lead to stroke,

heart attack or other medical complications.

What are the symptoms of High blood pressure? High blood pressure is often called the "silent killer" because symptoms are often lacking. Regular monitoring of your blood pressure is the only way to know if you have a problem.

Who is at greater risk? Those who have a family history of high blood pressure, those above 65 years old and young adults and middle aged African Americans.

What are the Risk Factors? They include diabetes, vascular disease, smoking, alcohol abuse, anxiety, high salt intake, obesity, birth control pills and illicit drug use.

High blood pressure is one of the major **treatable** causes of kidney disease. Treatment for high blood pressure depends on the type of high blood pressure and other factors related to the individual's condition.

In some cases it can be controlled with diet and control of fluid intake. Others may need medication or a combination of all the above. It is very important that a patient follows their doctor's orders and has continu-

ous medical follow up for this condition.

Some people who already have kidney disease develop high blood pressure. Almost all people whose kidney's have failed and who are on dialysis have high blood pressure.

Your dietician may tell you to cut back on protein and potassium and control your intake of fluids. It is important to take your medication as told as high blood pressure can lead to complications such as heart attack, swelling of the heart muscle and restricted blood flow that could lead to amputation of fingers and toes or death. It is up to you, as the patient, to follow your treatment team's instructions to avoid the complications that occur from high blood pressure.

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*.

Goodbye Pearlle Cole

It is with sadness that Network 13 says goodbye to Pearlle Cole, of Ft. Smith, AR. She was PAC member

from 1994-1996. Pearlle passed away on June 30, 1998. Her contributions to the PAC at the Network will allow her legacy to live on.

The Network expresses our condolences to her family, friends and those at her unit. Pearlle will be missed by all of us.

Travelling ESRD Style

You know traveling is fun. Nearly everyone likes it. However, for a dialysis patient it can be confusing and sometimes very scary. There are many factors dialysis patients and their families must consider before traveling.

Patients and their families are constricted to traveling in areas that provide a certain level of medical care. Your Social Worker can help you in making arrangements for dialysis while you travel and can assist in any needed paperwork and supply issues. The dialysis patients, hemodialysis and peritoneal, must locate a unit that provides the service they require. It is important to locate a hospital that also has the services you will require. The patient should always have a copy of their chart, with the basic information required for their treatment, with them in case of an emergency while travelling.

The hemodialysis patient has to travel in areas that provide dialysis. This is the first part of the problem. The second part of the problem is making sure that the area you are traveling to will accept transient dialysis patients. There are many areas in the U.S. that are not taking transient dialysis patients at this time.

After clearing up these points and having a place to dialyze, the patient should have questions to ask. These questions should provide the dialysis patient with confidence that the transient unit will give them the best of care while traveling.

1. While at the transient dialysis unit, who will be responsible

for any emergencies that come up?

This question is a very important one. It is the policy of most units to transfer care of a transient patient to the nephrologist responsible for the dialysis center. The patient should know who this doctor is and should have a 24-hour contact phone number. The patients also must know what hospital to go to in case of emergency. Everyone hopes that while traveling problems will not occur, but they do.

2. What type of dialysis machine does the unit use?

This question will give the patient an idea of what to expect when he/she arrives at the unit. If the machines are different than the ones the patient uses in his/her home unit, he/she might ask for a brief explanation of why the unit uses these machines. The patient might also ask for a generalization of the machine functions.

3. What is the reuse policy at the unit and what do you need to know about the policy?

The patient should ask about the reuse policy if staying at a unit for an extended period of time. This question lets the patient know if the unit is using reuse procedures. This avoids problems so that a patient who does or does not reuse can have arrangements made with a unit that meets that need.

4. When and how is the 20% co-pay for dialysis and related services made?

You will need to cover the expense of your co-pay with the unit you travel to. You need to ask how a payment can be made (check, credit card,

cashier's check and/or cash) so that you have this when you finalize arrangements. You also need to find out when they want that payment. Do they want it beforehand or at the time of dialysis treatment?

On a personal note there are several other questions that you may ask when travelling. The first is whether blankets and pillows are provided. This may seem like a trivial thing but many patients report getting cold during dialysis.

The second question you may ask is whether eating and drinking are allowed during treatments. A patient never knows when a transient treatment will be scheduled. Most often they are scheduled during off times and this question becomes important. You need to ask if you will have to bring any dialysis medication with you or what is the method of covering the 20% co-pay for when the unit provides it.

The final question you may ask is whether there are any other materials you should bring. For example, if the unit has television provided for each patient, sometimes they do not provide headphones or earplugs. Unless you can read lips, television without sound is pretty boring.

Most of these questions seem to be common sense. In the hubbub of packing for and scheduling a trip we often forget things. These questions may help prepare patients and assist their families in handling all the details so that all involved can have a safe and happy traveling experience. --Carl Nettleton

Patients in the Network

* Virgil Mills, hemodialysis patient from the Batesville, AR area received an Outstanding Toastmaster Award from his charter, White River Toastmasters. He received recognition from Toastmasters International for completing requirements for the Able Toastmasters award. Our congratulations to Virgil on his accomplishments. You are an inspiration for rehabilitation for others in the Network.



* Brian Hess, 17, a hemodialysis patient from Midwest City, OK was selected by the American Kidney Fund to be featured for the month of July in their 1999 calendar. Our congratulations to Brian on his effort and selection.

* O. Walter Morant was awarded the Life Option Renal Rehabilitation Council (LORAC) Award for his effort in the area of rehabilitation. This award was presented at the NKF National Convention in Philadelphia last October. Congratulations Walter.

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Medicare News

As of July 1, 1998 Medicare will cover blood glucose test strips, lancets and meters regardless of insulin use. Keep in mind: **1.** The benefits apply to people with either Medicare Part B or Medicare managed care coverage. **2.** Deductibles and co-pays for your Medicare policy may apply to these benefits. **3.** In order for Medicare to cover these benefits, a doctor must prescribe blood glucose testing supplies to you and document how often you need to test on the prescription. **4.** Your Medicare policy may define how many test strips and lancets you are entitled to each month.

Medicare has a new website, www.medicare.gov, to assist members with any questions they may have. Topics on the site include: **What is Medicare?, Managed Care, Who to Contact, Publications, Wellness, Fraud and Abuse.**

Medicare has its *1998 Guide to Health Insurance for People with Medicare* out. To obtain a copy call 1-800-638-6833 (TTY/TDD 1-800-820-1202)

UNOS Release

What Every Patient Needs to Know is a new booklet released by UNOS. It incorporates material from three previous brochures dealing with transplant issues. The new brochure provides information on preparing for transplant, developing a financial strategy, the transplant process, life after the surgery and promoting organ donation. Single copies are free and can be requested form UNOS at (804) 330-8602. There is a charge for bulk orders that can be placed at (804) 330-8541.

Website

Aging with Dignity, www.agingwithdignity.org, contains a free living will. The document entitled, "Five Wishes," complies with the law of 33 states.

AAKP UPDATE

AAKP has released the booklet *The Iron Story* to explain to patients and family members what to expect when using IV iron in the management of anemia. To order call the AAKP national office at **1-800-749-2257**.

AAKP has a limited number of copies of Mildred "Barry" Friedman's book *Strength and Compassion in Kidney Failure* Available. It is a collection of medical columns, short stories and letters of her journey with diabetes and ESRD.

Choices™ *Options for Living with Kidney Failure* is an educational video available for free rental at Blockbuster video stores. It is available in the community service section of the stores.



KIDNEY CONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for SPRING/APRIL. 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

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