

**ESRD NETWORK 13**

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# KIDNEY CONCERNS

SUMMER/JULY 2004

ISSUE 48

## Excerpt From Transplantation - "Now What? A Kidney Patient Handbook" - ESRD Network 13

Kidney transplantation is thought by many to be the "preferred" treatment of choice for patients experiencing kidney failure. Transplantation does have advantages such as a lifestyle free from dialysis therapy and fewer fluid and food restrictions. A kidney transplant, when successful, can often provide a better quality of life because it allows greater freedom and often is associated with increased energy levels. Some transplant patients, whose sexual activity declined with dialysis, find their sexual interest and activity level returning.

What is kidney transplantation? Kidney transplantation is the placement of a kidney from another person (donor) into a patient with kidney failure (recipient) through a surgical operation. The transplant operation involves an incision or cut on the lower part of the abdomen to connect the donated kidney to your blood supply and urinary system. The operation usually takes about three hours.

### The sources of kidney transplants are:

- 1) A living donor, related to you by blood
- 2) A living donor, NOT related to you by blood
- 3) A cadaver

Where do the kidneys come from? There are two types of kidney transplants: those that come from living donors and those that come from donors who have died (cadaver donor). A living donor can be someone in your immediate or extended family or maybe your spouse or close friend. An advantage of receiving a kidney transplant from a living donor is that the average long-term success rates tend to be somewhat higher than transplants from cadaver donors. Technical advances have improved the

success rates for people who receive cadaver kidneys. However, due to the shortage of donated organs, people must wait on a list until a suitably matched kidney becomes available. The wait time varies from patient to patient.

How do you decide if a kidney transplant is an option? There are many things to consider before deciding to get a kidney transplant. Your transplant center (transplant surgeon, transplant coordinator) will discuss all these issues with you at the time of your evaluation for transplant. Some of the issues include the risks and benefits of transplant, medications and their side effects, financial coverage and your ability to continue necessary follow-up care and to follow directions. Be sure and ask questions at your evaluation in order to be comfortable with your decision.

Medications? Anti-rejection medicines will be taken for the entire time that you have a transplant. These drugs have a number of side effects because they directly affect your body's immune system. Fortunately, most of the side effects are usually manageable. If they do occur, your doctor may adjust the dose of medicine to help. The most common side effects are high blood pressure, weight gain, ulcers, and a higher susceptibility to infections and tumors. Some cosmetic effects of medications may cause the patient difficulties. These changes include fullness of the face, acne, facial hair, stretch marks, fat pads on



the back, and darkened skin. Not all transplant patients have these problems and most of the effects can be made less noticeable through use of make-up, diet and other means.

Remember that the anti-rejection medications are to prevent your body from rejecting your new kidney. Your body's immune system guards against invasion by any foreign matter. This defense system may recognize your new kidney as "foreign" and act to combat this invasion. Frequent checkups are necessary to ensure early diagnosis of rejection. Additional treatment can often reverse rejection.


What about the financial issues? Medicare and private insurance cover most transplant and medication costs. Medicare covers 80% of the cost of the drugs you need to prevent transplant rejection and you pay the remaining 20% of the cost. At present, Medicare coverage remains in place for 36 months after the month of transplant. Remember that Medicare does not pay for all of the drugs that you may need to take. Other sources of financial assistance may be available. The social worker or financial coordinator at the transplant center are available to answer your questions.

## TRANSPLANTATION

### PRO'S

- Only potential way to replace renal function
- Frees the patient from dialysis
- Less dietary and fluid restrictions
- Improves feeling of well-being and normalcy
- May improve sexual activity

### CON'S

- Rejection risk
- Susceptible to infections
- Side effects from medications
- Cosmetic changes
- Cost of anti-rejection drugs 

## AAKP CREATES KIDNEY TRANSPLANT NEWSLETTER

TAMPA, Fla

The American Association of Kidney Patients (AAKP) is pleased to introduce its new, monthly electronic newsletter "Kidney Transplant Today." This newsletter is devoted to those who are interested in learning about kidney transplantation or those who have received a kidney transplant.


Beginning in July 2004, AAKP will electronically transmit "Kidney Transplant Today" on the first Tuesday of every month. The newsletter will feature important news about transplants, advances in medications, developments in research, new programs and materials about kidney transplants and much more.

Interested subscribers should send their name and e-mail address to [info@aakp.org](mailto:info@aakp.org). In the subject line, please type "Kidney Transplant Today."



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## How Long Has Your Fistula Lasted?

The Network is interested in finding out how many dialysis patients have had the same functioning fistula for ten(10) or more consecutive years. If this is you please contact your facility head nurse or social worker and have them report your accomplishment to the Network Patient Services (405.942.6000 ext. 3011. We look forward to acknowledging your success. 

## You and Your Medical Records

By: Sid Kirchheimer WebMD Medical News, Reviewed By Brunilda Nazario, MD  
on Monday, April 12, 2004

### Most People Never Read Their Medical Records, Despite Being Legally Entitled.

April 12, 2004 — Inside that manila folder may be the most significant story you'll ever read: Your doctor's appointment-by-appointment account of your health—or at least the attempts to preserve it. Yet most Americans have never read their own medical records, even though most want to, according to new research. Specifically, a survey of 4,500 adults indicates that one in three people say they are “very interested” in reading their medical records, while 43% said they were “somewhat interested.” So what's stopping them? Actually, nothing.

“Patients are legally entitled to access their own medical records whenever they want to, but many people don't realize they have this legal entitlement,” says researcher Jinnat B. Fowles, PhD, of the Park Nicollet Institute in Minneapolis. “There is an assumption by patients that their medical records somehow belong to the health care system and aren't to be routinely shared with them.”

Her survey, published in this week's Archives of Internal Medicine, is among the first to gauge the reasons why patients might want to review their medical records. Among the findings:

- Only one in four respondents had ever seen their own medical records. Those patients were nearly three times as likely as others to be “very interested” in getting this access.
- The most common reasons why patients wanted to read their records was to see what their doctors had written about them and to be more involved in their health—each cited by 74% of respondents and edging out the third most popular reason, “to better understand their medical condition.”
- Laboratory results were the most-sought after information, followed by doctor's notes. The least-sought information was past medications.
- Fewer than half of patients surveyed believed that their doctors would think it was “a good idea” for them to see their records.

“Medical records can be a powerful motivator, reinforcer, and educator. More people should be reviewing them, and all they have to do is ask, or maybe fill out a form,” Fowles tells WebMD. “But these results don't surprise me. Even among the significant minority of patients who did read their own records in the past, many didn't realize that they were allowed to.

“There is widespread lack of knowledge of being able to see your medical records. What's interesting is here is a book, and it's about you, and yet you probably haven't read it.” But don't expect your doctor to readily recommend this page-turner.

“Physicians are extremely hesitant to share the progress notes—the narrative part of a patient's medical records, whereas they rest easier about patients seeing their lab records and medications,” says Fowles. “That's because they have not thought of the patients as the audience, and this narrative is written for themselves and other clinicians.”

They may also want to avoid conflict with “editing” patients. Fans of TV's Seinfeld might recall the episode in which Elaine discovers her doctor has flagged her medical record with a warning—“problem patient”—and tries in vain to steal back her file. But in reality, such in-file notes detailing “non-compliance” might offer the only protection for doctors who treat patients who die or become seriously ill as a result of refusing to follow their medical advice.

Of course, doctors may also want to protect something else—their patients' egos. Just last week, the Institute of Medicine and the Agency for Healthcare Research and Quality (AHRQ) published reports indicating that nearly half of all American adults lack health literacy skills—that is, they have trouble understanding medical terms and directions to properly take medicine, describe symptoms, or fill out medical information forms.

“For the 90 million Americans with limited literacy skills, it's tough to read the front page of a newspaper or a bus schedule, much less the complicated documents that go along with being a patient in our country



today,” John C. Nelson, MD, MPH, president-elect of the American Medical Association, says in a prepared statement.

“More of us are slowing down when we speak to give patients time to understand what they’re hearing. We’re saying ‘high blood pressure’ instead of ‘hypertension;’ using plain English instead of confusing jargon. And more of us are asking patients to repeat the information we give them, in their own words.”

SOURCES: Fowles, J. Archives of Internal Medicine, April 12, 2004; vol 164: pp 793-800. Jinnat B. Fowles, PhD, vice president of research, Park Nicollet Institute, Minneapolis. WebMD Medical News: “Report: ‘Health Literacy’ Low in America.” American Medical Association.  
Reprinted under agreement with WebMD



### Caution – It’s High Potassium Season

By Susan Knapp

Potassium is one of the minerals that we get from the foods we eat. Although high potassium foods are always available, summertime is a time when high potassium foods are fresh and especially abundant. High potassium foods include potatoes, tomatoes, spinach, bananas, and cantaloupe. Normal kidneys remove as much potassium from the blood as is needed to keep up with however much potassium is eaten. When kidneys don’t filter as they should, potassium from the food can cause potassium in the blood to get too high, even to dangerous levels. The good news is that dialysis removes potassium easily. However, it can be quite easy to have too much potassium in the diet and build up dangerous levels between dialysis treatments. How much potassium that a dialysis patient can eat depends upon body size (larger people can handle more), if there is any residual urine function, excess losses from other ways such as diarrhea or vomiting, and what type of dialysis is being done. Since peritoneal dialysis (PD) is performed daily, total potassium in the diet usually does not have to be limited (although the potassium intake should be spread throughout the day on PD). Dietary allowances of potassium for hemodialysis patients usually are somewhere between 2000 mg. and 3500 mg. per day. A normal blood level of potassium is needed for the proper functioning of muscles and nerves. A high potassium level in the blood can cause an irregular heartbeat, possibly even causing the heart to stop. You will get some potassium from all of your foods, but should avoid excessive amounts. Even foods that are moderate in potassium, if eaten in unlimited portions, will contribute a large amount of potassium to your diet. Moderation in all things is a good adage. Because potassium dissolves in water, canned foods tend to be lower in potassium; for example drained canned peaches are much lower than fresh peaches. Since potassium is water-soluble, it is possible to remove some potassium from certain foods, such as potatoes, by “leaching” or “dialyzing” them. This involves peeling the potatoes, cutting them into small pieces, and soaking in a large amount of water, pouring the water off & then preparing as usual. This preparation method does not remove all of the potassium from the food, but might reduce it by half. Avoid salt substitute, which is potassium-chloride, because it is extremely high in potassium. Most importantly, pay attention to your portions & the number and size of servings that your dietitian recommends.

#### Potassium Poser

Rank the following foods from the highest to lowest in potassium (assuming equal portion sizes):

Strawberries, raw, sliced  
Potatoes, boiled in their skin  
Spinach, cooked from raw  
Cucumber, raw, sliced  
Pinto Beans

Milk, 2%

Broccoli, boiled & chopped, from raw  
Corn, fresh, cooked  
Tomatoes, fresh, chopped  
Peach, fresh, sliced



## Answers to the Potassium Poser:

Highest to Lowest Potassium (all  $\frac{1}{2}$  cup portion). Notice that many of these are really very close in their potassium content—therefore this was not an easy exercise! The values for the answers are based on the Food and Nutrition Information Center's website, which contains a large database of detailed nutritional information on many foods. <http://www.nal.usda.gov/fnic/foodcomp/search/>

- |   |  |
|---|--|
| 1. Spinach, cooked from raw = 420 mg.         | 6. Tomatoes, fresh, chopped = 200 mg.  |
| 2. Potatoes, boiled in skin = 296 mg.         | 7. Milk, 2% = 183 mg.                  |
| 3. Pinto beans = 247 mg.                      | 8. Peach, fresh, sliced = 162 mg.      |
| 4. Broccoli, boiled, chopped = 229 mg.        | 9. Strawberries, raw, sliced = 127 mg. |
| 5. Corn, fresh from the cob, boiled = 204 mg. | 10. Cucumber, raw, sliced = 81 mg.     |

### Summer Shrimp Pasta Salad

Dressing:  $\frac{1}{2}$  cup sour cream  
 1 lemon 1 teaspoon dried dill weed  
 $\frac{1}{2}$  cup mayonnaise-type salad dressing

## Salad Ingredients:

8 oz. medium shell pasta, cooked according to directions (leave out the salt)  
 $\frac{1}{2}$  cup green (or red) bell pepper, chopped  
 $\frac{1}{2}$  cup carrot, chopped  
 $\frac{1}{2}$  cup celery, chopped  
 $\frac{1}{2}$  cup green onion tops, sliced thinly  
 8 ounces shelled, deveined, cooked shrimp  
 1 cup cucumber, sliced

## Nutrition Information Per Serving:

Calories - 233; Protein - 10.6 grams; Carbohydrate - 28.1 grams; Fat - 8.7 grams; Potassium - 225 mg; Sodium - 190 mg.; Phosphorus - 110 mg.

Each serving = 1 Meat, 1  $\frac{1}{2}$  Starch, 1 Low Potassium Vegetable; 1 Fat (Yield - 8 servings)

Grate zest of the lemon and squeeze juice. Mix 1 teaspoon of lemon zest and 2 tablespoons of lemon juice with the salad dressing, sour cream, and dill weed.

- Rinse and drain the cooked pasta shells.
- Combine all salad ingredients.
- Pour the dressing over the salad ingredients and gently mix together.
- Refrigerate at least 30 minutes, or overnight.

### Blueberry Supreme

3 cups fresh or frozen, thawed blueberries  
 1 teaspoon lemon juice  
 $\frac{1}{8}$  to  $\frac{1}{4}$  teaspoon each of cinnamon and nutmeg  
 $\frac{3}{4}$  cup flour  
 $\frac{1}{2}$  cup sugar  
 $\frac{1}{4}$  cup butter or margarine  
 Whipped topping, optional

- Place washed berries in an ungreased 2-quart casserole dish. Sprinkle with lemon juice. Sprinkle the top with cinnamon and nutmeg
- In a separate bowl, mix together the flour and sugar. Cut in the butter until crumbly. Spread evenly over the blueberries.
- Bake at 375 degrees for 40 - 45 minutes or until top is lightly browned and berries are bubbling. Let it cool for  $\frac{1}{2}$  hour. Serve warm with whipped topping, if desired.

Recipe adapted from the Tulsa World, July 9, 2003.



**Nutrition Information Per Serving:**

Calories – 344; Protein – 3.1 grams; Carbohydrate – 57.2 grams; Fat – 12.4 grams; Potassium – 96 mg.; Sodium – 135 mg.; Phosphorus – 41 mg.

Each Serving = 1 Starch; 1 Low Potassium Fruit; 1 High Calorie Choices; 1 Fat (Yield: 4 servings)

4 Large Hard-Cooked Eggs  
1 Tbsp. Onion, chopped fine  
½ tsp. vinegar  
½ tsp. dry mustard

**Deviled Eggs**

2 Tbsp mayonnaise  
Pepper to taste  
Dash paprika

Halve eggs lengthwise and remove the yolks. Mash yolks with fork and add remaining ingredients. Mix well. Refill eggs, heaping slightly. Sprinkle with paprika.

Each serving contains:

Calories – 130; Protein – 6.3 grams; Sodium – 99 mg.; Potassium – .68 mg; Phosphorus – 89 mg.

Each serving = 1 Meat + 1 Fat (Yields: 4)



## AAKP PREPARES FOR ITS 31<sup>ST</sup> ANNUAL CONVENTION

TAMPA, Fla.

The American Association of Kidney Patients (AAKP) is making final preparations for its 31<sup>st</sup> Annual Convention to be held Sept. 2-5, at the Sheraton Bal Harbour Beach Resort in Bal Harbour, Fla. The city of Bal Harbour is conveniently located halfway between Ft. Lauderdale and Miami.

Titled, "Improving Quality: Patients Shaping the Future," this Convention promises to be informative and entertaining with topics for chronic kidney disease (CKD), dialysis and kidney transplant patients. With an average attendance of more than 500 people, AAKP's Annual Convention is the largest gathering of kidney patients and family members in the United States. AAKP strongly believes in the importance of education and self-care for all patients. As such, AAKP strives to include educational tracks at its convention for patients at all stages of kidney disease.

"AAKP has already secured highly respected speakers on a multitude of timely patient care topics for this year's convention. We are planning three days of excellent educational sessions to help patients understand their healthcare choices and empower them with the knowledge to lead full and healthy lives with kidney disease," said Kris Robinson, Executive Director of AAKP.

Convention attendees can expect to hear presentations on important and current subjects that affect today's kidney patients. Understanding the patient-doctor relationship, knowing your dialysis options, managing reduced kidney function, considering transplantation and public policy issues, such as patient advocacy, are just a few of the topics to be presented.

In addition to the educational sessions, AAKP's Convention offers a number of social events where attendees have the opportunity to celebrate life and share experiences with fellow kidney patients from across the country.

Registration fees for the three-day event are \$95 for patients and family members and \$150 for professionals. The convention package includes all educational sessions, two continental breakfasts, two dinners and one full breakfast.

Full details, including the Convention agenda, registration form and dialysis arrangements, will be available in the Convention brochure. AAKP members will receive a convention brochure in the mail. Non-members may also request the brochure and join the AAKP Convention mailing list by calling the AAKP National Office.

Hotel reservations can be made by calling the Sheraton Bal Harbour Beach Resort at (800) 999-9898. To receive the preferred rate of \$110 per night, please identify yourself as an AAKP Convention attendee.



Find the following high potassium foods:

Bananas  
Potatoes  
French Fries  
Tomatoes  
Cantaloupe  
Oranges  
Salt Substitute  
Honeydew  
Artichoke  
Avocados  
Beans  
Nuts  
Rhubarb  
Butternut  
Sunflower Seeds  
Spinach  
Mangos

B	E	A	N	S	A	M	F	G	S
A	H	R	O	A	D	A	R	C	D
N	O	T	S	L	C	N	E	A	E
A	N	I	P	T	P	G	N	N	E
N	E	C	I	S	O	O	C	T	S
A	Y	H	N	U	T	S	H	A	R
S	D	O	A	B	A	B	F	L	E
P	E	K	C	S	T	H	R	O	W
E	W	E	H	T	O	J	I	U	O
K	Y	R	N	I	E	F	E	P	L
Q	T	A	U	T	S	I	S	E	F
V	W	R	H	U	B	A	R	B	N
T	O	M	A	T	O	E	S	Z	U
B	U	T	T	E	R	N	U	T	S
L	X	M	O	R	A	N	G	E	S
S	A	V	O	C	A	D	O	S	B

Answers located on page 8.

### Dialysis Facility Compare

The Centers for Medicare & Medicaid Services (CMS) has announced the release of Dialysis Facility Compare in the “next generation compare” format that provides users with simple navigation within the tool. Users will be able to search for dialysis facilities by State, County, City, Zip or Name. Proximity searches are now available when searches are made on City or Zip. In addition, a search can be narrowed to specific services offered by dialysis facilities. Users will find new text explanations and a lower reading level. Users can also search for additional web resources by population (CKD, Children, Transplant, etc.)

The Dialysis Facility Compare(DFC) Web site ([www.medicare.gov](http://www.medicare.gov)) provides both demographic information and ‘quality measures’ data about dialysis facilities that have been approved by Medicare. What are the three quality measures?

- ✦ The percent of patients at a facility with Urea Reduction Ratio (URR) of 65 or greater (known as ‘adequacy of hemodialysis’).
- ✦ The percent of patients treated with Epogen® with a Hematocrit of 33 or greater. (URR and Hematocrit are based on 2002 data).
- ✦ Patient survival information.

The Web site also offers the dialysis facility characteristics.

- ✦ Address and telephone number of the facility
- ✦ The facility’s initial date of Medicare certification
- ✦ Shifts starting at 5 PM or later (if you need your treatments in the evening)
- ✦ The number of treatment stations
- ✦ The types of dialysis offered (in-center hemodialysis, peritoneal dialysis, and home hemodialysis training)
- ✦ Facility ownership type (profit or non-profit)
- ✦ Chain name (if applicable)

Before reviewing this data, be sure to view the Data Collection Details, Glossary, and adequacy, anemia, and survival data explanation, from the DFC Web site. The data is limited to Medicare beneficiaries and only those who are receiving hemodialysis.

## What Are My Options If I Have A Grievance?

### STEP 1

Try your facility first...  
 Contact your facility's social worker...  
 Ask for and follow the facility's written grievance procedures...  
 If not satisfied...

### STEP 2

Contact the Network...  
 Ask for the Patient Grievance Policy...  
 Visit our Web site for a copy of the policy...  
 Speak with the person in charge of Patient Services.

What is a grievance?

A grievance is any concern about treatment in a dialysis or transplant facility.

A grievance may be filed by the patient, a family member, or another person acting on the patient's behalf (per HIPAA guidelines). Grievances referred to the Network are processed according to written grievance procedures.

What is the Network?

Network 13 is under contract with the Centers for Medicare & Medicaid Services to serve the states of Arkansas, Louisiana, and Oklahoma.

The Network collects patient information and works to improve patient care and outcomes in dialysis and transplant facilities. Processing written grievances and trying to resolve patient concerns is an important part of the quality improvement program.

**Call 1.800.472.8664 for details.**

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Answers from page 7.

Answers:

B	E	A	N	S	A	M	F	G	S
A	H	R	O	A	D	A	R	C	D
N	O	T	S	L	C	N	E	A	E
A	N	I	P	T	P	G	N	N	E
N	E	C	I	S	O	O	C	T	S
A	Y	H	N	U	T	S	H	A	R
S	D	O	A	B	A	B	F	L	E
P	E	K	C	S	T	H	R	O	W
E	W	E	H	T	O	J	I	U	O
K	Y	R	N	I	E	F	E	P	L
Q	T	A	U	T	S	I	S	E	F
V	W	R	H	U	B	A	R	B	N
T	O	M	A	T	O	E	S	Z	U
B	U	T	T	E	R	N	U	T	S
L	X	M	O	R	A	N	G	E	S
S	A	V	O	C	A	D	O	S	B



## KIDNEY KONCERNS NEEDS YOU!

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