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KIDNEY CONCERNS

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Through It All.....God is in Control

By: Carolyn Wilson, PAC Member

Larry Banks began playing the saxophone at age eight. It has been his passion as long as he can remember. His passion led him to pursue a career in music. He received a degree in music while attending Langston University. He was employed to teach music but soon discovered he enjoyed playing music more than teaching.

Langston University not only provided Larry an education but introduced him to the love of his life. Larry and Pat Banks met while attending college at Langston University. They fell in love and married in May 1975. They have three children, two sons and a daughter.

Larry was diagnosed with renal failure in 1995 by the two leading causes, hypertension and diabetes. Larry's initial reaction to this news was denial. He spent five years trying to fend off dialysis. In April 2000 Larry went to his doctor's office to "get some fluid off" because he was retaining lots of fluid and feeling terribly swollen. At this point the dialysis staff and the nephrologist met with Larry and Pat to discuss his renal failure and his treatment options. Although Larry and Pat knew for some time he would need dialysis or transplantation, no amount of preparation could ready them or their children for what lay ahead.

Larry completed an evaluation for the transplant list. Larry and Pat's oldest son immediately tested to see if he could donate a kidney and was devastated to learn he was not a match. Their daughter experienced her own denial to the situation and believed if Larry could still work and play his saxophone then he wasn't really that sick.

Larry began hemodialysis with a catheter. Soon after a fistula was placed for his access. He had some problem with flow from the fistula. Several attempts were made to revise the fistula without success.


Larry made the decision to go on peritoneal dialysis. Pat was questioned about her reaction to this sudden change in the family and Larry's lifestyle. She responded the first reaction was she wanted Larry to do whatever he needed to make himself better. Pat also responded that at this point in her life, she believed that whatever was to happen was God's will. She believed God was in total control of everything that was to happen. Larry and Pat agreed that in their hearts they believed this to be another level of their life that God was seeing them through.

Regardless of the adversities he faced, Larry never stopped trying to do what he loved the most, playing the saxophone and to continue to take care of his family. He decided that whatever modality he chose, it would have to allow him to continue to do the things he loved.

Larry soon found peritoneal dialysis to be frustrating and felt too restricted. He felt it did not provide him the time he needed to complete his daily tasks as he wished. Things became difficult for Pat during this time as well. She felt she had to find a way to make her husband want to do his dialysis. She did not want him to be sick or to die. She resorted to threatening to leave him if he did not hook up. She would also have everything ready for Larry so he did not have any excuse to not do his dialysis.

Like a ray of sunshine through a cloudy sky, on September 12, 2003 Larry and Pat received the call from the transplant center. There was a kidney available for Larry. Pat recalls she handed the phone to Larry and paced back and forth wondering what was happening. She stated Larry just answered "yes" and


real nonchalant while she was on pins and needles. Larry finally hung up the phone and announced “well honey, we are getting a kidney”. Pat was so excited that she phoned everyone with the news while Larry got together his things for the hospital.

When questioned about the pros and cons of their ordeal from hemodialysis to transplant, Larry responded the he had no complaints and felt everything regarding his transplant went smoothly without any complications. Pat expressed she truly admired her husband through it all, “he just keeps striving, keeps enduring, he just keeps going”. Pat added with a big grin on her face “I am his biggest fan, he is my hero and I am just thankful to get my partner, friend, companion and lover back”. 

Rick Thompson : New Patient Advisory Committee Member

I would like to take a moment to introduce myself. My name is Rick Thompson and I am one of the newest members of the Patient Advisory Committee of ESRD Network 13. I suffered end renal failure due to a condition known as polycystic kidney disease. I began dialysis in August of 2001 after a lengthy hospital stay. I was blessed with a new kidney transplant in February of 2003.

Working with ESRD Network 13 is my way to offer counsel to people who are in a similar situation and give back to the system that has given so much to me.

The entire process of first kidney failure then dialysis can be overwhelming both mentally and physically. It places great burdens on relationships, work and life, as you have known it. In future issues of “Kidney Concerns” I hope to be able to address some of those issues from the eyes of someone who has seen the entire process for the inside. In closing, please remember that in all cases it takes both you and your health care providers to manage your health. Compliance is the key factor for maintaining good health and a positive outcome. 

Think that you can't change? Then think again

January 27, 2004 - By: Bob Condor The Chicago Tribune - <http://www.newsok.com>

You may be thinking what a lot of people are thinking: How did I break all of my New Year's resolutions already?

James Prochaska has a ready answer. Changing your behavior doesn't begin with action. Forget about, say, going cold turkey (yet again) on cigarettes or vowing that it is finally time to stop dating the wrong guy.

Start with making a decision to act differently. Prochaska, a professor and researcher at the University of Rhode Island, has developed a six- stage model about successfully making changes in lifestyle and health habits.

It is a previously reported system — one that helped millions of Rhode Islanders stop smoking — and well-worth the refresher course. Prochaska and colleagues are using it in a major government project to motivate people to exercise regularly. One study is focusing on teens and their parents, another on Americans who need to lose weight. You can apply it to re- upping on your broken New Year's resolution.

The first stage in Prochaska's proved model is called pre-contemplation. People in this stage have no plans to make a change such as working out, even if they occasionally promise themselves to get serious about exercise. Many people who join health clubs this month (the busiest time of year for clubs) are walking in straight from pre-contemplation.

What Prochaska recommends instead is discovering the benefits of regular physical activity. A good strategy is asking several friends why they exercise. Most important, ask them why they keep exercising.



For that reason, Prochaska isn't particularly fond of New Year's resolutions.

"We live in an action-oriented society," he said. "Most think the only options are take action or do nothing. The culture of the New Year's holiday feeds into that thinking."

The second stage of Prochaska's model is called contemplation. It marks progress in that people know that changing a health habit is good for them, but they are daunted by the task. Prochaska recommends two strategies here. One is to make a list of potential roadblocks to, say, quitting smoking, then develop ways to cope.

Another useful step during contemplation is discovering just how good a behavior change might feel. One example: Losing weight improves appearance — no small matter to most people — but can equally boost self-confidence, energy levels, clear thinking and much more.

"People know they should lose weight, but they simply underestimate the benefits," Prochaska said. "At the same time, they overestimate the cons or negatives of a situation."

The third stage is preparation. It is always a critical stage in Prochaska's work with people looking to make changes. He encourages people to have a good overall plan, such as consulting a physician to help with a weight-loss program, finding a workout buddy or identifying five takeout places where you get a healthy lunch. But he also recommends backup plans to allow for the inevitable "failure" that people feel when plans don't work smoothly. By the end of the preparation stage, Prochaska recommends that you make your intentions public by telling a loved one or any supportive person about your specific plan to change.

The fourth stage, action, requires the biggest commitment of time and energy. That's why Prochaska recommends telling a supportive loved one, friend or co-worker. We all need encouragement when the work is hardest. It all feeds into maintaining momentum until you can form a habit. Researchers have found it takes most of us at least three weeks to develop a new healthy habit. But your work is not done after 21 days, because the same studies indicate that it can take up to six months to break unhealthy habits.


The fifth stage of a successful change is maintenance. Prochaska's position is that you haven't developed a new habit until you have changed the behavior for six months. By then, your job is to develop strategies for preventing any relapse. He recommends keeping in mind the benefits of your new health habit and always putting fresh reasons on the list.

His sixth stage, termination, refers to the final sweeping out of a bad habit.

"Most people think unhealthy habits are because people don't have willpower," Prochaska said. "What we have found is it is more that people don't know how to change and keep the changes going. Once we help them realize the best strategies at each stage, they understand how free it makes them feel. ~~That keeps people going.~~"

Medicare Beneficiaries Could Face Large Part B Premium Increases Next Year, Actuary Says - March 26, 2004

Medicare beneficiaries who participate in Part B, which covers most outpatient services, could face premium increases of 17% next year, CMS chief actuary Richard Foster said at a discussion sponsored by the [American Enterprise Institute](#) on Thursday, [Cox News/St. Paul Pioneer Press](#) reports. According to the estimate, included in an appendix to the annual Medicare trustees report released on Tuesday, Medicare Part B premiums could increase from \$66.60 to \$78.10 next year, the largest increase since the program began. CMS will announce the official premium increase this fall. Foster attributed the estimated premium increase "primarily" to a decision by Congress last year to eliminate a scheduled 4.5% reduction in Medicare reimbursement rates for physicians in 2004 and 2005, according to [Cox/Pioneer Press](#). As part of the new

Medicare law, Congress approved a 1.5% reimbursement rate increase for physicians in 2004 and 2005. The trustees report also estimates that Medicare Part B premiums will increase to \$80 in 2006, \$82 in 2007 and \$85.60 in 2008. However, Foster said that because Congress likely “will again intervene to prevent” a provision in the Medicare law that would reduce reimbursement by 5% each year between 2006 and 2012, Part B premium increases could prove “far greater than predicted in the report,” Cox/Pioneer Press reports (Lippman, Cox News/St. Paul Pioneer Press, 3/16). 

Easy Renal – Friendly Meals

By: Susan Knapp, MS, RD, CSR, LD

One problem often heard from hemodialysis patients is that they don't have enough energy or time to cook what they should eat, particularly after their dialysis treatment. Some ideas that may help follow.

Take advantage of the times that you have more energy, usually on your non-dialysis days. Cook for more than one meal. Prepare extra food and put it in the freezer to have when your stamina is low. Making your own frozen dinners will allow you to more easily stay within your allowance of sodium and potassium than most convenience foods. Be sure to seal the foods well in freezer bags to keep them tasting fresh.

Some foods that work great as leftovers include meatloaf, many casseroles, roast turkey (off the bone), baked or boiled chicken (remove the meat from the bone) or pre-cooked crumbled hamburger. Cooking methods that prevent you from having to stand over the food while it cooks include using a crock-pot or small electric grill, or baking in the oven. Stir-frying can be another quick cooking method. Using paper plates and plastic ware saves on clean-up effort.

Easy Menu Ideas:

Scrambled or fried egg sandwich

Tuna sandwich (water-pack tuna, rinsed and mixed with sandwich spread)

Meatloaf sandwich

Chicken or turkey salad sandwich (using left-overs)


Salad using prepackaged lettuce mix topped with leftover meat or thawed frozen shrimp & boiled egg

Grilled chicken or hamburger on a bun with mayonnaise or Thousand Island Dressing

Cottage cheese with canned pineapple, pears, peaches or fruit cocktail

Stir-fry frozen chicken pieces or strips, or shrimp and frozen stir-fry vegetables served with unsalted instant rice

Frozen Meals:

In addition to frozen meals that you prepare yourself, you could keep a few “TV” dinners on hand. Since each meal should total about one-third of your total allowance, 700 mg. of sodium or potassium in a frozen meal would fit within a typical renal diet. Unfortunately, many of these dinners are much higher in sodium than this. Sodium (in mg.) per serving must be listed on the label. Most frozen dinner packages contain only one serving, but some are considered to have two or more servings. Another potential problem is that the amount of potassium and phosphorus in a food does not have to be listed on the nutrition label. Therefore, just because potassium or phosphorus is not listed, does not mean that it doesn't have a significant amount of it. For a clue, you can read the ingredient list. All nutrition labels must have an ingredient list. Try to eliminate dinners containing items that you know are high in potassium or phosphorus—such as potatoes, tomatoes, milk or cheese. Ingredient lists always include the ingredients starting from the largest and ending with the smallest by weight. From this you can “guess” whether the food is high in potassium or phosphorus. Another source of nutrition information is the manufacturer. You or your dietitian can contact the manufacturer. The contact information is on the label. The manufacturer may be able to provide you with the potassium and phosphorus content. 

On a recent field trip to our local grocery store I read the labels on all of the frozen meals. None of the labels had phosphorus information. Most brands also did not include potassium on the label. Some of the dinners with very similar names, even the same brand, varied greatly in sodium content. A few of the larger dinners had over 3000 mg. of sodium each—more than a day’s allowance! So, be sure to read the labels before you buy them. The frozen dinners that had potassium content on the label, containing 700 mg. or less of both sodium and potassium are listed below. There were other brands of dinners that had sodium levels less than 700 mg., but the potassium content was not included on the label. Based on the ingredient list, some of them would also be acceptable. Most of these dinners (listed below) are fairly low calorie and contain less protein than typically desirable for one meal. So—you wouldn’t want to rely on them all the time

Dinners Containing 700 mg. or less of Sodium and Potassium:

- ~ Lean Cuisine Dinnertime Selections: Grilled Chicken & Penne Pasta; Grilled Chicken Tuscan; Glazed Chicken; Grilled Chicken Caesar, Baked Chicken with Gravy, Stuffing and Whipped Potatoes; Chicken with Almonds; Sesame Chicken; Chicken in Peanut Sauce; Sweet and Sour Chicken; Glazed Chicken (with green beans, mushrooms and rice); Chicken a l’ Orange; Roasted Turkey Breast; Chicken Carbona; Chicken and Vegetables; Roasted Garlic Chicken
- ~ Stouffers Lean Cuisine Everyday Favorites: Swedish Meatballs; Roasted Turkey and Vegetables; Steak Tips Portabello; Chicken Chow Mein; Spaghetti with Meat Sauce; Mushrooms and Basil; Spaghetti with Meatballs; Hunan Beef and Broccoli with Rice; Roasted Chicken with Lemon Pepper Fettuccini
- ~ Weight Watcher’s Smart Ones – Bistro Selections: Fire Grilled Chicken and Vegetables

Easy Renal-Friendly Recipes:

Scalloped Corn
Serves 6

- 1 can cream style corn
- 1 package frozen whole kernel corn
- 2 eggs, well beaten
- 1 tsp. chopped onion
- 1 Tb. Vegetable oil
- ¾ cup non-dairy creamer

Mix all ingredients together. Pour into an oiled casserole dish. Bake for 25 to 35 minutes at 350 degrees.

Nutrient Analysis: 203 calories; 5 grams protein; 240 mg sodium; 228 mg potassium; 123 mg phosphorus

Recipe from Now You’re Cooking, Missouri-Kansas Council on Renal Nutrition.

Oven Fried Chicken

- Cut-up pieces of chicken breasts or drumstick
- Cornflakes

Place cornflakes in a large zipped bag and crush using a rolling pin. Rinse off the chicken pieces. Place the chicken pieces (1 or 2 pieces at a time) in the bag with the cornflake crumbs and roll or shake to coat. Place the coated chicken pieces in a pan that you have oiled or sprayed with non-stick spray. Bake in a 350 degree oven until tender, about 45 minutes.

Cottage Cheese Fruit Salad
Serves 6

- 1 15-oz. can mandarin oranges, drained
- 1 20-oz. can crushed pineapple, drained
- 1 ¼ cup frozen whipped cream
- 1 ½ cup cottage cheese (fat free)
- 1 3-oz. package gelatin dessert (orange or lime)

Mix together the first 4 ingredients. Stir in dry gelatin dessert. Refrigerate.

Nutrient Analysis per serving:
166 Calories; 3 grams Fat; 30 grams Carbohydrate; 234 mg sodium; 159 mg potassium; 82 mg phosphorus
= 1 oz. Meat, 1 medium potassium fruit, 1 fat



Free Print Versions of Life Options Kidney School(TM) Modules Now Available for Download

Madison, Wisconsin — In response to community requests, Life Options announces free print versions of its successful, on-line Kidney School modules (<http://www.KidneySchool.org>). The introduction and first four modules are now available to download from the Kidney School table of contents as PDF files, with remaining modules in production. These print documents will allow people without Internet access to benefit from the research-based information in Kidney School.

The purpose of Kidney School is to inspire, motivate, and empower people with chronic kidney disease (stages 3 to 5) to take an active role in their healthcare—and improve their chances to live long and live well. More than 130,000 users have visited the self-paced kidney learning center since its launch in March, 2002; an average of 6,000 visitors per month.

Life Options developed the PDF documents with all of the original content featured in the on-line version of Kidney School, minus the interactive components and the certificate of completion. The print versions feature a posttest, lively content, graphics, photos, and patient quotes. A multidisciplinary panel of Life Options Rehabilitation Advisory Council (LORAC) members and patients and professionals from the renal community reviewed all Kidney School content.

Life Options is administered by the Medical Education Institute, Inc. of Madison, WI, and supported by Amgen Inc. For free, research-based materials or more information about how to live long and live well with kidney disease, please visit the award-winning Life Options Web site at <http://www.lifeoptions.org>, call (800) 468-7777, or e-mail lifeoptions@MEIresearch.org.

Dialysis Facility Compare

Where do you go when you need information on other dialysis facilities in your area? A patient asks what unit in his area offers peritoneal dialysis or home dialysis, could you tell whom to contact? You have a patient that needs evening dialysis due to his job, could you tell him what unit offers evening hours? You want to compare your facilities quality measures with the units in your area, is there a place to go to find this? Now you can. The Dialysis Facility Compare (DFC) Web site 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 survival data is based on the period from January 1999 to December 2002.

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.

Word Search

Find the following high in potassium or phosphorus ingredients that you may find on a label's ingredient list. Remember that the largest ingredient (by weight) is listed first and the smallest ingredient (by weight) is listed last. The hidden words can be forward or backward, across or down. Letters may be used more than once.

Find:

- Potatoes,
- Tomatoes,
- Potassium
- Chloride,
- Milk,
- Phosphoric Acid,
- Chocolate,
- Nuts,
- Molasses,
- Beans,
- Buttermilk,
- Dry Milk Solids,
- Parmesan
- Cheese, Cheddar
- Cheese,
- Romano Cheese,
- Baking Powder,
- Phosphate,
- Pecans,
- Peanuts.

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

Answers on page 12



Are You Ready For Whatever Mother Nature Brings?

Spring is a time of growth and renewal, but unfortunately it is also the time for severe weather. Are you prepared? Would you know what to do when a tornado is on the ground, or how to prepare for a hurricane, if in your immediate area?

“Be prepared” is a good motto to follow and is a must for severe weather conditions. Below we have listed several safety facts and supplies to have on-hand for weather emergencies.

Plan ahead. Develop a plan of action. Appoint a designated person to be in charge during the emergency. Weather information from NOAA Weather Radio and local radio/television station needs to be monitored. (Battery radio is preferred, since lose of electricity is a possibility).

Be educated. Learn how to return your blood and disconnect the lines. Know where the “safe place” is located at your facility, (interior room, in a hallway, or basement and away from windows).



American Kidney Fund Offers Toll-Free Help Line to Spanish - Speaking Callers in Time for National Kidney Month

To: National Desk, Health Reporter

Contact: Sandra Palmer of the American Kidney Fund, 301-984-6657

ROCKVILLE, Md., Feb. 26 /U.S. Newswire/ — The American Kidney Fund announced its new, toll-free Help Line for Spanish speaking callers who need information about chronic kidney disease (CKD). March was National Kidney Month, and launching the new service reflects the Fund's expanded efforts to address the alarming growth in the incidence of kidney disease in the U.S. American Kidney Fund Executive Director Karen Sendelback said, "Hispanic Americans have nearly twice the risk of kidney disease as non-Hispanic Caucasians. In fact, one out of every eight people with kidney failure in the U.S. is Hispanic. There is no cure for kidney failure; the only treatments are kidney dialysis and kidney transplantation."

The Fund is helping to address the high incidence of CKD among Hispanic Americans by raising awareness of the disease, and by targeting those at risk through its Minority Intervention and Kidney Education (MIKE) program. The Spanish Help Line (866.300.2900) will support the larger initiatives by providing information about the prevention and treatment of kidney disease to Spanish speaking callers.

Overall, about 20 million people in the U.S. have impaired kidney function, and more than 400,000 have end stage renal disease (kidney failure). The American Kidney Fund's general toll-free Help Line (800-638-

8299) has been providing callers with valuable information about kidney disease for more than a decade.

The American Kidney Fund is the nation's leading voluntary health organization serving people with and at risk for kidney disease through direct financial assistance, comprehensive education, clinical research and community service programs.

Answers To Page 8 Puzzle:

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



KIDNEY CONCERNS NEEDS YOU!

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

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