



# Windows of Our World

## *Patient Advisory Committee*

*Western Pacific Renal Network #17*

October 2010

The **Patient Advisory Committee (PAC)** was established in January of 2010 with patient representatives from Network #17. They provide insight to the Network on patient-related issues and concerns that involve improving patient centered care and quality driven outcomes.

The purpose of the PAC is to advise the



Patient Advisory Committee pictured from left to right: Coleen Laudari, Iris Barnett, Sarah Ellsworth, Diane Sammons and Mike Brady

Network response to patient needs and seek ways to improve patient/staff relationships. The PAC is led by Chairperson Mike Brady and is advised by the Community Outreach Coordinator and Director of Operations. The five member committee of dialysis patients

were nominated by facility Social Workers because of their desire to improve the quality of ESRD patient care.

### **Goals of the PAC:**

- Identify and present needs and concerns of renal patients
- Act as a liaison between patients & Network #17
- Promote patient empowerment & involvement in healthcare issues
- Develop & provide patient education to be used in the renal community at large

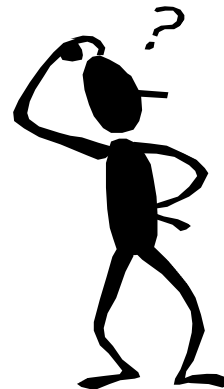
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## What Is Network #17 and What Can They Do For Me?

The Network is available to all patients and providers when there are questions, concerns and/or complaints. It is our goal to promote patient's knowledge and involvement in their care, promote patient rehabilitation and serve as a resource to the renal community. The strategic goals of the ESRD Network Program are to:

- ◆ Improve the quality and safety of dialysis-related services provided to individuals with ESRD
- ◆ Improve the independence, quality of life, and rehabilitation (to the extent possible) of individuals with ESRD through transplantation, use of self-care modalities, in-center self-care, as medically appropriate, through the end of life
- ◆ Improve the patient perception of care and experience of care, and resolve patient complaints and grievances
- ◆ Improve collaboration with providers and ensure achievement of goals through the most efficient and effective means possible with recognition of the differences among providers
- ◆ Improve the collection, reliability, timeliness and use of data to measure processes of care and outcomes



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## Holiday Eating for Dialysis Patients

### *The BEST Way to Remove Half the Potassium from Potatoes and Yams*

Research has been done to find the best way to remove the most potassium from tuberous vegetables such as potatoes and yams. Your dietitian might refer to the process as “double cooking” or “leaching” or even dialyzing potatoes. ***This does not turn potatoes into a low potassium food.*** They are still considered high potassium but ***double cooking*** will remove about **half** of the potassium.



1. Wash and peel the vegetable.
2. Slice the vegetable into thin slices.
3. Place the sliced vegetable in a pot with room temperature water. Use two times the amount of water to the amount of vegetable.
4. Bring the water to a boil.
5. Drain off the water and add fresh, room temperature water. Again, use two times the amount of water to the amount of vegetable.
6. Bring the water to a boil again and cook until the vegetable is soft and tender.

*Continued on page 4*

## *Travels with Iris*



*Iris Barnett is a four year hemodialysis patient originally from Philadelphia who loves to travel! Writing is her “spice of life!”*

Dialysis patients can travel the world! All you need is the desire to travel, places you want to visit, and careful planning. As a dialysis patient at Elk Grove since October of 2006, I have enjoyed many years of traveling around the country. In 2008 I travelled from California to the east coast and spent three weeks traveling from Philadelphia to New Jersey, New York, Connecticut, Rhode Island, and Massachusetts.

My first hemodialysis day on vacation was scheduled for 2 PM Thursday in Salem, New Jersey. My dialysis technician was very impressed that my California doctors cared enough to give me a catheter since my fistula wasn't working.

Friday morning after a great breakfast with the family at Cracker Barrel and a

little shopping we were off to Atlantic City for seven days.

The dialysis center in Atlantic City was located just a few blocks away from the hotel which made it very convenient. In this center I was able to “surf the internet” during my three hour treatment. This seemed to make my treatment go by faster and the staff was great.

I was very thankful for a timely run because yes, I had a standing date at the casinos and didn't want to keep them waiting.

The boardwalk was great with some new renovations which made walking, riding the push buggies, shopping and sight-seeing much easier and more fun.

Our next stop was Cape Cod, MA and Martha's Vineyard. The weather for nine days had been a little bit of everything from clear all the way to snow flurries in Philadelphia. However, on this October day, the sun was bright and the temperature was about 45-50. Seeing the coast this way was incredible and it's difficult to describe the beauty of an incredible fall season.

The dialysis center in New Bedford, Massachusetts was 18 miles away from the resort and it would give me more of a chance to see the state. There were other centers closer and one in-center on Martha's Vineyard, but my time on the Vineyard was

*Travels with Iris continued from page 3*

my fun time not dialysis time. Martha’s Vineyard offers many types of tours including an African American tour. I chose a private auto tour and my driver was a local jazz musician who shared many of his experiences as well as sang and played the harmonica for me. Yes, I was there celebrating when Barack Obama won the Presidency. How grand was that?



As the plane lands in Sacramento, CA on November 11, I remembered my vacation adventure: all the fun, going to church, having dinner with my family, great cheese steak sandwiches from Pat’s ( home of the original cheese steaks), mustard pretzels, Philadelphia cheesecake and of course Tastycakes (I had packed them away for home).

I am truly very thankful to God for my life, even my life after dialysis and thankful for my medical team. If I can travel so can other dialysis patients. What are you waiting for?

**Go, go, go!**

*Holiday Eating continued from page 2*



For those who have diabetes, ½ cup potatoes contains 15 grams of carbohydrate and 1/3 cup sweet potatoes or yam has 15 grams of carbohydrate which is equal to 1 starch or bread serving.

Potassium Content of Tuber Varieties		
White potato	1 cup, cubed, with skin	632 mg
Sweet potato	1 cup, cubed, raw	448 mg
Yam	1 cup, cubed, raw	1224 mg

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**Marianne Hutton, RD, CSR, CDE** holds a Bachelor of Science in Nutrition and Dietetics from the University of Detroit–Mercy College. She is certified by the National Certification Board for Diabetes Educators and is Board Certified as a Specialist in Renal Nutrition. Marianne serves as the dietary advisor to the PAC.

## *Conversations with Diane*

### **Surviving the Lobby**

Some are chatting amiably about the news with a couple of other “Lobby People.” Others sit quietly, staring at nothing. Unexpressed feelings abound in the small room - a room simply meant for waiting. But we do so much more than wait. We want to yell “hurry up in there.” Some want to strike up a conversation, any conversation, to feel less isolated and lonely. Others want to complain about the frustration of waiting for their rides which are late once again.



Someone asks if we know that “Mrs. Johns” passed. We react but one cannot see it. That deep fear rises up in our throats. We say, “sorry to hear that,” and we breathe a little heavier. We turn to look at the door.

In all its emotional forms, vulnerability and feelings of helplessness underscore much of the lobby chatter or silence.

We are much more than a group of patients waiting for our name to be called. We have a special bond that can't be seen so easily. We feel each other's tension, others fear of

change, even the change of chair number to which we are called. We silently hurt when ignored or spoken to curtly when others are busy.



Some smile and say they understand. No one wants to be understanding all the time. We see this in each other. We inherently know these things. That is our special bond.



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This writer is a San Francisco dialysis patient and a retired registered nurse. Ideas for discussion and any comments are welcome.

## Holiday Word Search

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

**Word search instructions:** As you look for the hidden words, remember that they can be horizontal, vertical, diagonal, frontward or backward! Once you've found a word, simply circle it. Good luck!

*Tree**Cranberries**Witches**Turkey**Feast**Presents**Snowman**Pumpkin Pie**Ghosts**Star**Costumes**Trick or Treat**Santa Claus**Pilgrims**Candy*

## Don't Feel Like Cooking? No Problem!

### SALMON BURGERS BY OCEAN BEAUTY

The American Heart Association recommends two servings of fatty fish a week but canned salmon is often salty and fresh salmon means a trip to the market. Additionally some days you just don't feel like cooking.

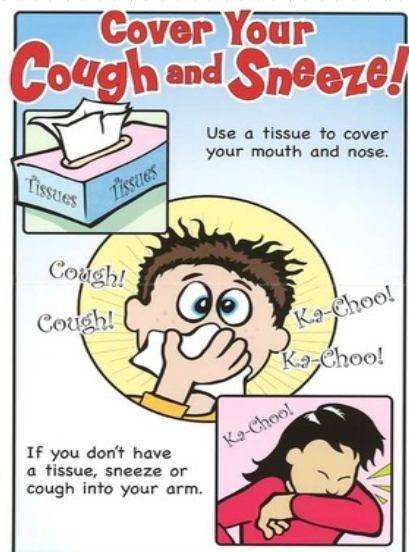


Reach into your freezer and grab a box of **Ocean Beauty Sea Choice** frozen salmon burgers. They come as *Seasoned* or *Herb Crusted*. Put a burger or two on your counter-top cooking grill or into your toaster oven, pan or regular oven. In only 15 minutes your delicious *Seasoned* patty is ready to put on a whole grain bun with some sliced cucumber, lettuce and onion. Toss on a slice of tomato if it's included in your potassium allowance for the day. A patty contains 16 grams of protein and 500 milligrams of the omega-3 fats DHA plus EPA, all for just 120 calories and almost no saturated fat. The "seasonings" translate into just 1 gram of sugar and 230 milligrams of sodium.

The yummy *Herb Crusted* patties don't have quite as much protein (12 grams) and omega-3's (310 mg) because the breading replaces some of the salmon. But for those needing more calories they are higher (200) and the sodium (240 mg) is still quite reasonable. Even the staunchest non-fish fans will enjoy the light, crispy breading.

The salmon is wild Alaskan and the burgers are available at Albertsons, Safeway and Target. A box of four 3 oz. patties will run you about \$4.50. Just add a fresh coleslaw or cucumber or green salad and fruit and you have a delicious and nutritious meal!

Ocean Beauty: (206) 285-6800



## Flu Prevention Tips

- Cover your nose and mouth
- Wash your hands
- Avoid touching your eyes, nose or mouth
- Try to minimize contact with other people
- Follow local public health advice
- Get your flu shot

## *Are You Prepared for an Emergency?*

- Know your dialysis unit emergency policy and procedures
- Keep your emergency information up-to-date and with you
- Know your disaster diet and review it frequently with your dietitian
- Remember that your **VASCULAR ACCESS** is for dialysis only!
- Keep a current list of your medications and allergies and extra medications on hand
- Prepare a home disaster kit with any emergency supplies and/or home dialysis supplies
- Keep important papers and cash with you
- Have a back-up plan for transportation
- Be Prepared Year Round!

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### **DON'T FORGET TO MAKE A PLAN, GET A KIT, BE INFORMED**



In case of...

**Fire** — Get out, stay out. Call 911.

**Earthquake** — Drop, Cover and Hold.

**Flood** — Do not walk or drive through moving water or into flooded areas. Seek higher ground.