

Bay Area Association of Kidney Patients

Kidney Connections

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Spring 2008 Issue

Welcome to the third edition of the newsletter for the Bay Area Association of Kidney Patients!

The Bay Area Association of Kidney Patients is a new organization formed to educate and support Bay Area kidney patients.

For questions or comments about this newsletter:

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April Meeting on Renal Diets a Rousing Success!

By Debra Elmore

Judging by the attention and questions from the audience, the April 13 Bay Area Association of Kidney Patients meeting on Renal Diets was a rousing success! About 70 attendees heard four speakers talk about renal diets and even participated by taking the "Buffet of Choices" quiz to win prizes.

The day started with an entertaining presentation by Marianne Hutton, RD, CDE. Ms. Hutton is a lecturer, author, and consultant



Marianne Hutton enthuses about kidney diets specializing in diabetes, renal nutrition, and lifestyle improvement.

She recently co-authored a book, "Kidney Friendly Comfort Foods" with Katie Lee Joel. Ms. Hutton explained how a kidney friendly diet consists of individual modifications in calories, protein, sodium, potassium, calcium, phosphorus, fluid, carbohydrates, fat and cholesterol.

In general, kidney patients that are not yet on dialysis should see a registered dietitian (RD) to devise a nutritional plan designed to stop or delay the progression of their kidney disease. Once on dialysis, patients automatically have access to a RD who, upon request, will advise a different nutritional care plan that will bolster the immune system and increase their strength and vitality. Ms. Hutton stressed that each kidney patient is unique and that an ongoing relationship with a RD is critical in maintaining optimal health and meeting the ongoing challenges that the various stages of kidney disease present. Her web page is mhutton.mydiabeteseducator.org

Next, LuAnne Aakhus and Calvin Wong from DaVita, the sponsors of this meeting, gave a presentation on the DaVita Diet Helper. The Diet Helper is an online (www.davita.com/diethelper/) meal planning tool designed to help people plan and follow their kidney diet. The Diet Helper tool is specifically designed for late Stage 4 and Stage 5 kidney disease patients and monitors protein, potassium, sodium and phosphorus intake. This tool helps you plan meals, has healthy, kidney friendly recipes, has a nutrition log, and even will give you a printable shopping list!

Patsy Obayashi, MS, RD, CDE from Stanford



Patsy Obayashi explains the Post-Transplant diet

(Continued on page 2)

(Continued from page 1)

Hospital and Clinics, then spoke about the Post-Kidney Transplant Diet. Ms. Obayashi discussed how, once you have a transplant, all the kidney diet rules that you used to follow change. The need for your body to heal from surgery and the effects of the anti-rejection drugs can cause appetite changes. One universal rule for transplant patients is not to eat grapefruit because it can cause your body to absorb too much of the medication you are taking. Weight management is also a big issue in post-transplant patients. In general, post transplant patients should follow the healthy diet and lifestyle recommendation of the American Heart Association:

www.americanheart.org/presenter.jhtml?identifier=851

Our last speaker was Patrick J. Barron, a kidney patient who followed the "Walser Diet" that allowed him to delay dialysis for three years until he received a transplant through a donor exchange program. The diet is based on the book, "Coping with Kidney Disease: A 12-Step Treatment Program to Help You Avoid Dialysis," by Mackenzie Walser, M.D.



Mr. Barron discusses the very low protein diet!

Dr. Walser takes the traditional kidney diet to the next level by strictly restricting protein intake but requires the daily addition of essential amino acids supplements to maintain good nutrition. Dr. Walser claims that in many patients the diet actually worked to slow or arrest the progression of kidney failure to the end stage. There is controversy about the Walser diet; you should talk to your nephrologist before starting it. However, Mr. Barron credits the diet with helping him manage his albumin, potassium, phosphorus, etc. levels, and feel good even when his creatinine hit the low teens in the days before his transplant.

Who Are We?

Who are we? We are the Bay Area Association of Kidney Patients (BAAKP) a new, volunteer, non-profit group of kidney patients, ancillary professionals, and interested participants. This organization was formed in the summer of 2007 with the purpose to **EDUCATE** and **SUPPORT** San Francisco Bay Area kidney patients. We publish four newsletters a year and have four general meetings a year, featuring topics of interest to kidney patients and their families. Past meeting subjects have included:

- Staying Ahead of Chronic Kidney Disease
- Developments in Living Kidney Donation, and
- Dealing with Your Kidney-Friendly Diet.

The June 22nd meeting features a panel of experts discussing Financial & Insurance Solutions for Kidney Patients (see page 6).

Possible future meeting topics include presentations by a dermatologist, the organ donor network, emergency preparedness for kidney patients and transplant hospitals.

Name our Newsletter Winner!

At this time, we are pleased to announce the winner of the contest to Name our Newsletter! The winner is Shar Carlyle of San Rafael, with the name KIDNEY CONNECTIONS, who wins a one-year membership to the National AAKP. Congratulations, Shar!

Other Local Kidney Support Groups & Meetings

T.R.I.O
Transplant Recipients International Organization
 Silicon Valley Chapter
 Meets on the 2nd Thursday of each month at 7:30 pm. El Camino Hospital, Cafeteria Meeting Room, 2500 Grant Road Mountain View, CA 94040
www.bayareatrio.org
 408-353-2169
 No meeting in June—picnic instead

Contra Costa Dialysis Support Group
"Patients Helping Patients"
 4th Tuesday of each month
 January - October
 Carl's Junior Restaurant
 2280 Oak Grove Rd
 Walnut Creek, CA
Contact: Tom and Kathie McClish
 (916) 332-1086 OR Paul and Marie White (925) 934-4883
For: Dialysis patients and their loved ones, staff members

The National Kidney Foundation
 (NKF) of Northern California has many resources available and sponsors many events.
 For more info:
www.kidneync.org
 415-543-3303

BAAKP Member Receives Kidney in Historic 6-Way Transplant at Johns Hopkins

A first-person account by Jeanne Heise

On March 24, 2008 I got the call from my transplant coordinator at Johns Hopkins proposing a six-way (12 person) paired exchange transplant. Were we interested?

I am a polycystic kidney disease patient, who has been suffering from end stage renal disease for three and a half years. I was rapidly reaching the point of needing dialysis. After three and a half years of waiting on the transplant list at Stanford, and an estimated three and a half years to go to reach the top of the list, we, my husband

this case, an elaborate 12 person swap. We needed to make our decision quickly, and, if we agreed, needed to be in Baltimore (for probably 1 month) by the following Wednesday for our pre-op work-up. After conferring with my local nephrologist, we concluded this would be a good opportunity to receive a live, matching organ. We said yes.

On Saturday, April 5, nearly 100 medical professionals, including 9 transplant surgeons, took part in the historic six-way, twelve person, transplant. The transplants began simultaneously in six operating rooms with the six donors. As each do-



President George W. Bush meets with The Johns Hopkins Hospital Organ Donors and Recipients Wednesday, April 23, 2008, in the Oval Office of the White House. Said the President after, "I was pleased today to meet with organ donors, medical professionals, and organ recipients -- all of whom participated in a historic six-recipient kidney transplant, in which six patients received new organs from six unrelated living donors. These people are all first-hand witnesses to the gift of life—or in this case, lives." White House photo by Joyce N. Boghosian (Jeannie is on the right of the President, holding the scrub shirt; her donor is the tall woman in the dark dress on the left; her surgeon is the white-coated Dr. with glasses and a green tie on the left; the altruistic donor in the man in the tan suit behind the lady in the wheelchair.)

and I, decided to explore other alternatives for organs. My husband was willing to donate, but was not a compatible blood type. In August of last year, we went to Johns Hopkins to be evaluated for their incompatible kidney transplant program. After extensive testing, we were accepted as a donor-recipient pair. Our wait in the Hopkins program began.

This March 24 call was the call we had been waiting for — they had found a match for us, or in

nor's organ was harvested, the room was cleaned, and the recipient was rolled into the same operating room to receive the live kidney. The combined surgeries stretched over ten hours. This was the largest, and most complicated matched kidney swap in history and Johns Hopkins achieved it with military precision.

The donors and recipients came from North Carolina, Michigan, Idaho, Massachusetts, California, and Pennsylvania. *(Continued on page 4)*

(Continued from page 3) The pairs included two married couples, two friends, two cousins, a mother/daughter pair, and one altruistic donor and a recipient off the national waiting list.

In our case, all donors and recipients did well. Donors were released from the hospital within a few days. The first recipient was released after five days, and the rest were released within 10 days of their transplants. Most recipients stayed in the Baltimore area for another month or six weeks for follow up care.

This event was a remarkable example of generosity and compassion. The transplants, coincidentally, took place during National Donate Life Month. In recognition and appreciation of the historic nature of this organ swap, the donors, recipients, and medical professionals were invited for a visit with President Bush in the Oval Office of the White House. In a statement issued by his office, President Bush acknowledged "The selflessness of those who are donors is an inspiration...I urge all Americans to make the decision to donate."

There have been 301 matched kidney swaps in the United States since the early 2000's, with the majority occurring between two pairs of donors and recipients. Johns Hopkins has performed 52 paired kidney exchanges. Hopkins pioneered the first triple swap in 2003, the first five-way swap in 2006, and the first six-way swap with this procedure. While this type of paired exchange is available at a limited number of medical centers, it is thought that a national system to bring mismatched pairs together could add about 2000 additional transplants a year, which would go a long way to reducing the waiting time for organs.

For all of the recipients, this swap seriously shortened the time spent waiting for a transplant. "It takes six people off the list and gives each the best possible kidney—a live kidney—and allows six other people to advance on the list," said Dr. Robert Montgomery, chief of transplant at Hopkins.

As one of the recipients, I can tell you it was a personal blessing, a transforming gift of life, and one for which I will be eternally grateful.

ATTENDEES TEST THEIR KNOWLEDGE OF THE CKD DIET AT THE APRIL MEETING



Ginny Mayer & John Ireland ponder the choices

	CHOICE A	CHOICE B
1	Angel Food Cake	Chocolate Layer Cake
2	White bread	Whole wheat bread
3	Power Bar	Rice Krispies Bar
4	Orange juice	Cranberry Juice
5	Box Mixed Pancakes	French Toast
6	Coca Cola	Ginger Ale
7	Cream Cheese	Strawberry Yoghurt
8	Ben & Jerry's Ice Cream	Raspberry Sorbet
9	Yellow Winter Squash	Green Zucchini
10	Hot Chocolate	Hot Herb Tea

As part of the recent BAAKP Meeting on Renal Diets, attendees had a chance to be tested on their knowledge of the Chronic Kidney Disease Diet. Prior to the guest speakers, audience members studied the CHOICES and marked their papers. At the conclusion of the meeting, the highest scorers were awarded donated prizes including dinners, massages and books.

You can take the same quiz. Pretend you are a Chronic Kidney Disease patient who is not yet on dialysis; would choice A or choice B be the best choice for you? (Answers are on page 5.) Curious to know why one choice is better than the other? Email us at bay.area.kidney@gmail.com for explanations.

11	Baked White Potato	White Rice
12	Split Pea Soup	Vegetable soup
13	Applesauce	Banana
14	Watermelon	Cantaloupe
15	Guacamole Dip	Cream Cheese based dip
16	Cabbage	Brussels Sprouts
17	Apple pie	Pumpkin Pie
18	Rice Krispies	Granola
19	Hamburger (no tomato)	Cheeseburger
20	Mixed nuts	Popcorn

BAAKP Joins NKF Kidney Walk on June 21, 2008

The **Bay Area Association of Kidney Patients** will be participating as a team in the National Kidney Foundation's June 2008 Kidney Walk/Run. The event takes place on June 21, 2008, from 9 am to 1 pm, in San Jose at City View Plaza. The NKF of Northern California and Northern Nevada has, most generously, allowed our fledgling organization to participate in this **5K WALK/10K RUN** event as a means of raising money for BAAKP activities. All funds raised by BAAKP participants and supporters will be designated for the funding of BAAKP events! WOW!

The BAAKP is a new volunteer organization, whose goal is to EDUCATE and SUPPORT Bay Area kidney patients and their families. Organizational costs for quarterly General Meetings run about \$1000 per event and production costs for each quarterly newsletter are about \$500. Through group participation in this Walk/Run, BAAKP hopes to raise sufficient funds to support the upcoming 2008/2009 events and newsletters!

We hope that many of the quarterly meeting attendees will consider participating in this event. Supporters of BAAKP can participate by being a

walker or runner, and also by soliciting additional sponsorships and donations from co-workers, friends, and family.

To participate, in the NKF Kidney Walk, register with NKF (National Kidney Foundation) by:

1. Go to <http://walk.kidney.org/siliconvalley>
2. Click "Join A Team"
3. Search for "Bay Area Association of Kidney Patients"
4. Join the team and enter your registration information.

You may also contact Erika Zlatkoff at the Kidney Walk office at (415) 543-3303 x 103 to register over the phone.

If you'd rather donate directly to BAAKP or sponsor a BAAKP team walker or runner, there are also directions on the website for that. Questions about registration, sponsorships, and donations can also be addressed to BAAKP at Bay.Area.Kidney@gmail.org or to Erika at NKF Erika@kidneyca.org.

Garage Sale Nets Money and Fun!

On Saturday, May 3rd, 2008 BAAKP volunteers rose early to help set up the many tables and racks of donations for our annual garage sale. Co-Chairs Anne Griffin and Bea Goodman, along with Walt & Linda Umbach, spent several Friday afternoons sorting and pricing the many items. Sam Goodman, Walt Umbach, and John Hatfield served as cashiers. There were constant shoppers from 8 AM to 4 PM. Children's clothes and accessories sold very well. Unusual finds included a dance hall mirrored ball, which finally sold after being hung on the mailbox! The total take was \$639.00 which was added to our Treasury to support the upcoming General Meetings and Newsletters! Thanks to all who donated their "stuff," time and money!

BAAKP Seeks Corporate Sponsors

As you have most likely gleaned from the articles on this page, our young organization doesn't have a rich Uncle Harry or Aunt Zelda. We exist solely on the funds we raise from activities such as Garage Sales and our participation in the Kidney Walk. And, now because we are affiliated with the National Kidney Foundation, we are in a position to accept tax-deductible donations to support our mission to EDUCATE and SUPPORT Bay Area kidney patients. The folks at DaVita have supported our recent meetings, but we also believe that other kidney-related and perhaps non-kidney-related companies, non-profits, and family and business trusts might also see our goals as worthwhile. If you wish to donate or know of any possible donors, please let us know at bay.area.kidney@gmail.com.

Answers to Diet Quiz: 1A, 2A, 3B, 4B, 5B, 6B, 7A, 8B, 9B, 10B, 11B, 12B, 13A, 14A, 15B, 16A, 17A, 18A, 19A, 20B.

Bay Area Association of Kidney Patients

Educating and Supporting Bay Area Kidney Patients

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*Newsletter publication dates are November, February, May and August
If you've received an extra copy of this newsletter, please pass it along!*

SAVE THESE DATES!

General Meetings:

- **June 22, 2008**
Sunday, 1:00 pm
**"Financial & Insurance
Solutions for Kidney
Patients "**
- **October 19, 2008**
Topic to be announced

Events

- **June 21, 2008**
**BAAKP team participates
in the NKF Kidney
Walk/Run**

Steering Committee Meetings

**First Tuesday of
every month at 6:30 pm**

*If you would like to join us in the
leadership of this group, we would
love to have your help.*

(Call for location)

**bay.area.kidney@gmail.com
650-326-2107**

June 22nd Meeting to Feature Expert Panel on Financial & Insurance Solutions for Kidney Patients

The Bay Area Association of Kidney Patients has gathered a powerhouse panel of 6 experts for the June 22nd meeting to answer the many financial and insurance questions posed by kidney patients. The BAAKP has discovered that financial questions arise at most meetings so this should be a popular topic!

The meeting will take place at 1:00 pm on Sunday, June 22nd, at Sequoia Hospital, Sequoia Room, 170 Alameda de las Pulgas, Redwood City, CA 94062. Reservations are strongly suggested as seating is limited.

The expert panel includes Deanna Dooley, LUTCF, JD, local Insurance Broker; Diana Grey, Program Manager from HICAP (Health Insurance Counseling and Advocacy Program), which is a

free service for Medicare Beneficiaries; Debbie Mast, Transplant Financial Coordinator from Stanford Hospital's transplant program; Vanita Chhatpar, from Care Plus, a specialty pharmacy dealing with transplant medications; Adam Zapala, J.D. from Bay Area Legal Aid; and a dialysis social worker from DaVita.

Bring your questions about Medicare, insurance, and other ways to finance kidney disease expenses. This is the time to get them answered! Refreshments will be served and a short social hour will follow from 4 to 5 pm.

To reserve your seat, email us at bay.area.kidney@gmail.com or call us at 650-327-2107. You may also fax your reservation to 650-327-0178 or mail to BAAKP, Box 2332, Menlo Park, CA 94026-2332.