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Bay Area Association of
Kidney Patients

Kidney Konnections

Who & How—Kidney Transplant Disparities

We were honored to have **Vanessa Grubbs, MD, MPH**, Associate Professor, Division of Nephrology, University of California, San Francisco, as a speaker at our May 2018 Educational Presentation. She is the author of a new book entitled ***"A Kidney Doctor's Search for the Perfect Match."*** Dr. Grubbs talked about how to get through the progression from dialysis to transplant. She described her personal experiences with a young male patient (who later became her husband), and to whom she donated a kidney, as a guide through the system.

A chart of the steps a patient goes through to be ready for transplant published in 1998 by JAMA (Journal of the American Medical Association), shows 98% of blacks (compared to whites) reach step A ("Medically Suitable and Probably Interested"). At step B it drops to 68% ("Definitely Interested"). At step C it drops again to 56% ("Pretransplant Workup Complete and on Waiting List").

Finally, at step D it drops to 50% ("Moved Up Waiting List and Received Transplant").



Sadly, in 2017, a UNOS (United Network for Organ Sharing) chart showed 47% of transplants going to whites, 27% going to blacks, and 18% going to Hispanics. Therefore, as Dr. Grubbs emphasized, the picture of minorities receiving a kidney transplant has not improved much in the past 19 years.

Next, Dr. Grubbs illustrated with statistics from the US Renal Data System for 2017, showing that ESRD occurs three times as often in blacks as whites, and one and a half times as often in Hispanics as whites. On the supply side, she showed statistics which revealed 71% of living donors are white, 9% are black and 14% Hispanic. These statistics also revealed that 68% of deceased donors are white, 14% are black and 14% are Hispanic. Dr. Grubbs pointed out that 13 people die every day for lack of a kidney transplant. The basic problem is that we do not

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The Bay Area Association of Kidney Patients

is a volunteer non-profit 501(c) 3 organization with the

Mission to Educate and Support Bay Area Kidney Patients

Attend the Educational Presentations and Support Group Meetings, read the *Kidney Konnections* newsletter and visit our website at www.baakp.org

Eating Your Way Through Kidney Disease



Ms. Lauren Budd Levy, MS, RD, CSR, of Satellite Healthcare, joined our May Educational Presentation to help us understand the kidney diet. Kidneys perform many functions: removing excess water and solutes, removing toxins & drugs, secret-

ing hormones, producing active Vitamin D, and controlling the production of red blood cells.

What you eat can help control waste products, and you will feel better, no matter what your stage of kidney disease. The goals of a nutrition therapy (aka the kidney diet) are to preserve kidney function as long as possible, preventing waste product buildup in your system, and balance fluids and electrolytes (sodium, potassium, phosphorus, calcium, etc.) Remember, your diet recommendations may differ depending upon your stage of kidney disease, your type of dialysis, and your lab reports.

To preserve kidney function: Control your blood pressure by reducing salt, both table salt and salted foods. (Ed. note: High blood pressure can be both the cause and result of kidney damage.) If diabetic, you must manage your blood sugars by aiming for a reading of 80-130 (mg/DL) while fasting; 2 hours after a meal your blood sugar should be under 200. In addition to diet, exercise can help with blood sugar control.

Protein is necessary to build and repair muscles and tissues; maintain bones, skin, and hair; and make enzymes, hormones, and body chemicals to fight infections. However, dialysis removes protein! The best proteins come from meat, fish, poultry, and eggs. One ounce of lean beef, pork, skinless poultry, fish or shellfish = 7gm protein. Plant

proteins, such as beans, lentils, tofu, nuts, seeds also have protein but are high in phosphorus.

Fluid control: Kidneys regulate fluid balance. A fluid is anything liquid at room temperature. Fluid control is very important for the dialysis patient. To maintain fluid control, add 1000 ml (4 cups) to your urine output. If your urine output is 2 cups, your fluid intake can be 6 cups. Beware of the cup sizes at restaurants and the grocery store. A small McDonalds drink is 2 cups!

Salt (sodium) regulates the amount of water in your body. Eating too much salt can increase thirst and blood pressure; overwork your heart and lungs; and cause swelling from retained fluids. Try to avoid table salt: ½ tsp=1180 mg of sodium! Also avoid garlic salt, sea salt and remember salt substitutes may be high in potassium; **read the labels!** Note the servings per container and the milligrams of sodium. It's best to eat home cooked foods where you can control salt. Other sources of sodium are condiments, processed and canned foods.

Which Is Highest in Sodium?



See answer at end of article

Potassium is the next element your kidneys control. When your kidneys are damaged, they struggle to move potassium from the blood to the urine! Too little or too much potassium can cause

(Continued on page 4)



have enough kidneys to meet the demand for transplants so how can we develop a fair and equitable distribution of those kidneys available for transplant?

Dr. Grubbs pointed to the many disparities in our present system; in who gets ESRD, in who donates kidneys, in how kidneys are

allocated, and in access to the wait list for a transplant. She suggested disparities in who gets ESRD could be affected by access to healthy food, safe neighborhoods, clean air, a good education, and to health care. Dr. Grubbs went on to say the differences in who donates kidneys could be influenced by public awareness about who can donate to whom, awareness about donor evaluation, and awareness about dialysis and

ESRD. Dr. Grubbs found that when you dig into people's attitude about kidney donation you find out about all kinds of ethnic and religious traditions as well as massive amounts of misinformation hindering donation; so education is paramount. She added that she would encourage everyone to sign up as a donor on their drivers license and be sure to tell their family of their intent. She showed us two charts which showed a big change towards a more equal distribution of deceased donor kidneys by UNOS as a result of the latest revision of their regulations. Finally, Dr. Grubbs suggested that disparities in access to the wait list for a transplant could be changed by patient education, the implementation of a standard referral system, and transparency for the patient.

Thank you Dr. Grubbs for your time!

Dr. Grubbs can be reached at
Vanessa.grubbs@ucsf.edu or 415-206-5649

A Special Thanks to...



Our May Educational Presentation volunteers: (left to right): Ray Olivares, Anna Mae Olivares, Ashley Henderson, Amelia Basler, Rudy Reed, and Verdie Reed

Our Volunteers!

Without the many people who contribute to the Bay Area Association of Kidney Patients (both in time and money), our organization would not be able to function. You may recognize the volunteers pictured to the left. In addition to helping with our May Education Presentation, these wonderful people consistently have helped us “pull it together” for our educational events. They help hang signs, register participants, take pictures, make sure the sound system is working, man the food tables, set up the literary table — if it needs to be done, they will jump in and do it. We want to say a special “thank you” to them.

Thank you for volunteering and giving our organization the most precious thing you will ever own — your time and talent.

**The printing, postage, and website distribution of this newsletter
is supported by a grant from
the Palo Alto Foundation Medical Group Community Health Care Endowment Fund
Thank you for your support!**

This newsletter is not intended to take the place of personal medical advice,
which should be obtained directly from your Doctor.

serious health problems. Potassium helps muscles and nerves communicate and is in fruits, vegetables, dairy, nuts, and beans.

Phosphorus is a mineral which builds healthy bones. However, high phosphorus can lead to bone disease and heart disease. Phosphorus is naturally present in dairy products, whole grains, nuts, beans, and chocolate. Phosphorus is also an added ingredient in many processed foods to improve taste and lengthen shelf life. Read the labels! Favorite hiding places for phosphorus are sodas, flavored waters, iced teas, processed food, fast food, and instant foods. Above all, avoid foods with any words containing "phos." Your doctor may prescribe phosphate binders (which work like a sponge) to soak up the excess phosphorus from your meals.

Calcium is a mineral that builds healthy bones; it also is important to your heart and nerves. However, you must **avoid too much calcium**. Calcium is in dairy foods, kale, broccoli, and sardines. Calcium-fortified foods include juices, breakfast cereals, bottled waters, and energy bars. Other sources include calcium-containing phosphate binders, Tums for heartburn, multivitamins, and dialysis liquids.

Vitamins, formulated for kidney patients, can be prescribed by your doctor, but **avoid all herbal products**; they can cause serious adverse effects.

Transplant: Be the best candidate you can be by maintaining a healthy weight with a BMI $\leq 36-38$, keeping blood sugar controlled with a target of HbA1c of 7 to 8%, and having optimal nutrition with blood albumin equal to or greater than 4.0.

Our thanks to Ms. Levy for helping us to understand the kidney diet. Ms. Levy can be contacted at levyla@satellitehealth.com.



Sodium Answer:

... Are you Surprised?		SATELLITE HEALTHCARE NUTRITION • MEDICATION • EDUCATION
• 1 cup Corn Flakes (204 mg)	}	Ham & Cheese Sandwich: 870 mg sodium!
• 1 slice of American Cheese (270 mg)		
• 2 slices White bread (280 mg)		
• 1 slice ham (320 mg)		
• 1 cup canned vegetables (350 mg)		
• 4 slices turkey breast (550 mg)		
• 1 slice cheese pizza (640 mg)		
• 1 cup Campbell's Classic Chicken Noodle Soup (790 mg)		
• 1 cup o' noodle (1000 mg)		

* See page 5 for Daily Needs Chart

Let's give a special thanks to those people who make BAAKP what it is!

Board of Directors

Christie Chapman
Debra Elmore
Robert Neal
Linda Umbach
Walt Umbach
Marcus Wong
Phillip Wyche

And to countless Speakers,
Sponsors, and Volunteers



Follow us on Twitter, @baakp, or navigate to twitter.com/baakp.

For those new to Twitter: it is a way for us to send (or "tweet") out a short message, or a "tweet." It might be to share an inspiring news story, educational health tip, or updates about one of our past or upcoming meetings. You can read these messages anonymously— or you can sign up for a Twitter account to tweet your own message and to follow us. You may also want to install the Twitter app on your mobile phone to tweet and receive tweets while on-the-go. It is simply a way to quickly network and connect.

Daily Needs	Chronic Kidney Disease (CKD)	Hemodialysis	Peritoneal Dialysis	Post Transplant
Calories	13.6 to 15.9 Calories/pound of weight; e.g. 150 lb person should eat 2040-2380 Calories per day	13.6 to 15.9 Calories/pound of weight; e.g. 150 lb person should eat 2040-2380 Calories per day	13.6-15.9 Calories/pound of weight; e.g. 150 lb person should eat 2040-2380 Calories per day, including calories from dialysate	Maintain optimal weight; may need less calories if meds cause weight gain
Protein Lab value as albumin normal ≥ 3.4 , dialysis ≥ 4.0	Limited to preserve kidney function. 0.27 to 0.36 gm protein/pound of weight; e.g. 150 lb person can eat 41 to 55 gm protein per day	At least 0.54 gm protein/pound every day to maintain muscle; e.g. 82 gm per day for 150 lb person	Need to eat more protein to offset losses from PD 0.54 to 0.59 gm protein/pound; e.g. 82- 88 gms for 150 pound person.	Acute after surgery 0.59-0.91 gram per/pound of body weight; e.g. for 150 pound person, 88-136 gms per day. Maintenance 0.36 to 0.45 gm/lb or 54-68 gms/day
Fluid	Not usually restricted in early stages.	1000 ml (4 cups) plus urine output	Maintain fluid balance	Not restricted
Sodium	Limit, no added salt	2000 mg/day	2000 mg/day	Control blood pressure
Potassium Lab value: Normal 3.5-5.0, Dialysis 3.5-5.9	Not usually restricted in early stages	Blood levels indicate requirements; usually 2000-3000 mgs/day	Unrestricted or mildly limited to 3000 mgs/day	Blood levels and medications dictate requirements
Phosphorus Lab value: Normal 2.7 - 4.6, dialysis 3.5-5.5	Maintain normal blood phosphorus	10-12 mg/gm of protein For example: 150 lb person requires 82 gm protein per day; he should limit phosphorus to 820 to 984 mg phosphorus per day		Higher, may need supplement
Calcium Lab value: normal 8.5-10.2, dialysis: 8.0-10.2	Maintain normal blood calcium	2000 mg per day (from food dialysate, meds and binders) Extra calcium doesn't necessarily go to bones; it may deposit in heart & blood vessels.		Extra may be needed because of calcium loss with some transplant medications; suggest 1500 mgs/day
Vitamins & Minerals	Daily renal multi-vitamin (if prescribed by doctor)	Water soluble vitamins are lost to dialysis, yet fat-soluble vitamins may accumulate abnormally. Renal vitamins, generally Vitamin B Complex with C		Multivitamin

Recipe—Vegetable Dip*

1 pkg 8 oz cream cheese, softened
½ cup margarine, softened
3 T green onion chopped
2 T mayonnaise
1 T vinegar
1 ½ t. lemon juice
1 ½ t. hot dry mustard
1 t. horseradish
1 t. paprika
½ t. garlic powder
½ t. tarragon
Dash cayenne pepper

2 Tablespoons per serving provides:

Calories 155
Carbohydrates 2
Protein 2
Fat 16
Sodium 133
Potassium 43
Phosphorus 28

* from the NKF Cookbook,
Living Well on Dialysis

Kidney-versaries!!

The BAAKP would like to recognize our members who have had a kidney transplant. If you would like your name in a future newsletter, let us know the date of your transplant.

Donna Reynolds	November 8, 2004
Marina Gudino	November 9, 2010
Phil Wyche	November 22, 2013
Debra Elmore	October 23, 2014
Jon Lee	November 30, 2014
Robert Neal	December 26, 2016
Joan Grealis	November 14, 2017
AnnaMae Olivares	January 2, 2018

BAAKP Support Groups

A new BAAKP Support Group!

On August 12, 2018, the BAAKP held its very first San Francisco support group. The event was held at the California Pacific Medical Center-Pacific Campus at 2333 Buchanan Street and 17 people attended. Dr. Steven Katznelson, Transplant Nephrologist; Tara Pollock, Inpatient Kidney Transplant Coordinator; and Alexandra Ho, Licensed Clinical Social Worker attended and represented CPMC.

Although it is unusual for us to have medical professionals at our support groups, it opened the door for us to discuss detailed medical questions with professionals.

As with all of our support groups, the discussions covered a wide range of topics with all stages of kidney disease represented. We had people with CKD (Chronic Kidney Disease), dialysis patients (both hemodialysis and peritoneal dialysis) and transplant recipients. Support groups are a great way to learn about kidney disease and to meet other people who have been where you are now.

Our next two San Francisco support groups are December 2, 2018 and March 24, 2019. The meeting is held from 1–3 pm at California Pacific Medical Center, 2333 Buchanan Street, Level A Conference Room (walk through the cafeteria to get to the conference room). No reservations required! We hope to see you there.

Read about our experiences with kidney disease!

And then please donate to the Bay Area Association of Kidney Patients



Compliance, education and persistence led to a kidney transplant despite being HIV positive!

Read more at

baakp.org/greg.html



It took awhile for me to learn to take care of myself. But now, I am a happy transplant recipient!

Read more at

baakp.org/bobby.html

I knew I wanted a living donor kidney transplant, but I was surprised with the results of my Facebook post!

Read more at

baakp.org/anne.html



My wife and I fought our way through the VA system to a transplant at CPMC with our daughter as a donor in a transplant chain.

Read more at

baakp.org/james.html



I got in "under the wire" to receive my deceased donor kidney transplant at the age of 78 !

Read more at

baakp.org/jerry.html



I neglected my health, despite being a medical professional, and had to go on dialysis; but now I have a transplant.

Read more at

baakp.org/annamae.html

Please consider BAAKP for your year-end donations.

Participate with an online donation at

baakp.org/donate.html



or mail your donation to: BAAKP > PO Box 2332 > Menlo Park, CA 94026

**And your donation will be matched, dollar for dollar,
up to \$5,000, by an anonymous BAAKP member!**



Bay Area Association of Kidney Patients

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***Educating & Supporting
Kidney Patients!***

Please visit our website at
www.baakp.org
to make a donation, read back
issues of our newsletters, and view
videos of our past meetings. Your
help is greatly appreciated!



SAVE THESE DATES !

Peninsula Events

Palo Alto Medical Foundation-3rd Floor
795 El Camino Real, Palo Alto, CA 94301

Support Group Meetings (1-3 pm)

- Jan 13, 2019
- Apr 7, 2019

East Bay Support Groups

Alta Bates Summit Hospital
Merritt Pavilion Rm 1776
350 Hawthorne Ave, Oakland, CA 94609
(BART-MacArthur station)

Support Group Meetings (1-3 pm)

- Feb 10, 2019
- May 5, 2019

San Francisco Events

California Pacific Medical Center (Pacific Campus) -
Level A Conference Room
2333 Buchanan Street, San Francisco, CA

Support Group Meetings (1-3 pm)

- Dec 2, 2018
- Mar 24, 2019

Board of Directors' Meetings

1st Tuesday of the month—6:00 pm
info@baakp.org (650) 323-2225

Save the Date! March 10, 2019 Skin Cancer and UC Davis Transplant

Mark your 2019 Calendars for our next Educational
Presentation on **Sunday, March 10, 2019**, from 1 to 3 pm!

The location has been changed to **Alta Bates Medical
Center, Auditorium 6 & 5, 2450 Ashby Avenue, Berkeley,
CA., 94705.**

Our speaker from U.C. Davis will be **Eric
Huang M.D., Chief, Department of
Transplant Nephrology**, discussing the UC
Davis kidney transplant program.

Our second speaker will be **Sarah Arron,
MD, PhD.**, a dermatologic surgeon, who is
director of the **High Risk Skin
Cancer Program at UCSF**,
which cares for patients who are at risk for skin
cancer due to organ transplant.

Save the date for this **FREE** event.

Registration will open after January 1, 2019. If
you have questions, please contact BAAKP.

