# **Kidney Konnections**

A publication of the

#### Volume 4, Issue 4

#### September 2011 Fall 2011 Issue

The Bay Area Association of Kidney Patients is an allvolunteer, non-profit , 501(c)3 organization formed to educate and support Bay Area kidney patients. Visit us at www.BAAKP.org

## **Chapter Officers**

Grant Bennett President Marco Martin Vice President Hispanic Liaison Walter Umbach Recording Secretary Debra Elmore Newsletter Editor Bea Goodman Hospitality Anne Griffin Development John Hatfield, PhD Librarian Raj Kelkar Hospitality Scott Kessler Programs Tom Ko Webmaster Ben Lee Webmaster Willie Mackey Community Outreach Coordinator Linda Umbach Programs Marcus Wong Development Phil Wyche Hospitality

### Advisors

Toby Gottheiner M.D., Medical Advisor Betsy Bucter, R.N. CPMC Liaison



# May Meeting Focused on Kidney Friendly Diets

#### By Marco Martin

At our spring presentation the BAAKP welcomed two speakers to discuss the science of a kidney friendly diet. The meeting focused on both technical and creative information that kidney patients could use. In the long run, food is a type of medicine since it affects health and our overall feeling of well being. Our two guests, Marianne Hutton and Jessica Goldman, gave us a spirited presentation of their knowledge and welcomed questions from our inquisitive audience.

Marianne Hutton is a registered dietician, certified diabetes educator, and board certified in renal nutrition (only approximately 400 dieticians in the US have both the CDE and CSR certifications) and has a practice in the North Bay. Marianne began by providing a brief overview of kidney disease which included some interesting facts. For instance, there doesn't have to be protein in the urine in order to diagnose kidney disease. A glomerular filtration rate (GFR) of less than 60 for over three months (obtained from a blood test) qualifies as chronic kidney disease (CKD). Knowing your GFR is a good idea since CKD is currently a "growth industry" – as

many as 1 in 9 people have some form of this condition. The GFR number also indicates the patient's current

you are on dialysis (during Stage 5 or end stage CKD), your diet will have to be modified again. But



Marianne Hutton and Jessica Goldman

level of the five stages of CKD. A GFR test is ordered when a doctor suspects a patient of having kidney disease for any of a variety of reasons. This can include symptoms of tiredness, loss of appetite, diabetes, or just having a family history of CKD.

Ms. Hutton repeatedly emphasized that a dietician must tailor a diet to the individual since every person and situation is different. Configuring a renal diet involves blood tests, dietary guidelines from your nephrologist, and the overall wellbeing of the patient. Diet control becomes important around Stage 3, and once there are ways to modify your diet at any stage to produce beneficial health effects.

The first condition partially controlled by diet is high blood pressure. High blood pressure is generally seen in CKD patients in all stages and only about half of the cases are well controlled. Your dietician can help

with a strategy that will most likely include 30 minutes of physical activity per day and a low sodium diet. Medication is just a part of treating high blood pressure; controlling sodium intake is also important because too much sodium can cause fluid retention or edema.

Usually at Stage 5, anemia becomes the other big complication. This is due to a low red blood cell count and is characterized by tiredness. In this situation, a dietician would try to get your red blood cell count (or Hgb for hemoglobin) to between 11-12 g/dl of blood.

#### (Continued from page 1)

Prior to dialysis, to protect remaining kidney function, Ms. Hutton recommended limiting daily protein intake to 0.6 grams/lb of body weight. But be careful with ingesting too little protein since this can lead to another serious condition, malnutrition. A diet that is not well planned can also result in a low potassium level. Thus a dietician is a good teammate to keep someone from eating too little of what they need as well. Mrs. Hutton also advised to avoid simple sugars and keep saturated fats to less than 7-10% of your daily calorie intake (1g of fat = 9 calories). Plus, plant proteins are a healthier option since they lead to less inflammation. Plant proteins include nuts, soy, and beans.

An important tool for the hemodialysis doctor and dietician is the ability to alter the dialysis baths (dialysate) in order to remove more or less of specific waste products. The bath can be formulated to remove the expected wastes as determined by a patient's diet. The more adherence to the diet translates to more efficient dialysis treatments.

Kidney disease leads to low or high calcium and vitamin D levels and higher than normal amounts of phosphorus in the blood. This discord causes too much activity (or too little) in the parathyroid gland which can leave bones in a brittle state. The key element to control is phosphorus, for when it causes the blood calcium to rise above 10.2 mg/dl, hardening of the blood vessels begins. Besides being the most challenging ingredient to control, phosphorus has been on the rise in our food over the last 10+ years. Chickens are injected with this additive to make them plumper. There is now more phosphorus in the American diet than at any time in the past. Even worst, you won't see a rise in blood phosphorus until it is too late. The element is not required to be on food labels. However, avoiding animal protein means you avoid a major source of phosphorus. You must become aware of the phosphorus content in the foods you eat by doing your own research.

Our next speaker was Jessica Goldman. Not too long ago, while she was in college she diagnosed with an auto-immune disease that effectively destroyed her kidneys - she was in complete renal failure. She is not a doctor or dietician but has an online blog where she hosts many creative kidney friendly recipes (and is affectionately known as Sodium Girl due to her goal of avoiding salt). She decided to learn as much about her condition as she could on her own. She combined her new knowledge with a dedicated effort to heal and has since impressively regained some of her lost kidney function. Since her recipes use no sodium she has learned to use many other ingredients to flavor food. She encourages all to alter their perspectives. Just as in a game of charades you need to find other creative ways to communicate, so it is when you are told to avoid salt in the diet. You discover new and exciting

things you would not have otherwise known. She told us that the U.S.D.A. has an informative online nutritional database and is one of her best resources.

About 70% of the sodium in our diet comes from processed food, not the salt shaker. Over time the salt additives in our food has increased without us knowing.

She notes that people need to give their taste buds time to adjust to natural ingredients. Thus they need not get discouraged if they aren't following their new diet well at first. Her creativeness has led her to create her own bagels out of seaweed and sesame. Tomatoes and bell peppers could be a good replacement for Ragu (if you don't have to watch your potassium levels). I even caught a mention of macaroni and peas. Ms. Goldman is an inspiration when it comes to illustrating how dedication can change someone's life.

Our guests also fielded questions from our audience and, as always, provided some eye opening answers. For example we were told that juicers are not good for diabetics (due to sugar) nor to those restricting triglycerides. Also, eating the same thing everyday, however healthy, can lead to the build up of some chemicals. These then start to become toxic to us. A vitamin supplement is also not a bad idea, but in CKD Stages Four or Five it should be a renal vitamin only and only with your doctor's permission.

These and other interesting tidbits of information also captivated our audience. To learn more about the BAAKP, its presentations and how you can attend, please visit our website at **www.baakp.org**. Video of our program can also be accessed online on our website. A special thank you is given to Mrs. Marianne Hutton and Ms. Jessica Goldman for making time to share their valuable knowledge for the benefit of us all, the kidney community.



Marianne Hutton addressing the BAAKP audience

## Tomato Free Ketchup Recipe from Sodium Girl (Jessica Goldman)

Many kidney patients need to watch their potassium intake. As a result of question asked by an audience member at our May presentation, Jessica Goldman (Sodium Girl) developed this great recipe for Tomato Free Ketchup. You can read her blog entry and find the recipe online at:

sodiumgirl.wordpress.com/2011/05/27/low-sodiumlow-potassium-ketchup/

#### **Tomato Free Ketchup**

- 3 cups pureed red bell peppers (about 3 large bell peppers + food processor or blender)
- 3/4 cup apple cider vinegar
- 1/4 cup brown sugar
- 1 teaspoon black pepper

In a small pot, bring all the ingredients to a rolling simmer over medium heat. Cover with a lid and cook until reduced by 1/3, about 15 minutes. If using right away, keep the ketchup warm on low flame with pot covered. Or, if it is being saved for later use, place in an airtight container and refrigerate. Ketchup will stay good for one week.

This newsletter is not intended to be a substitute for advice from your medical professionals. Please consult your physician or other medical professionals about any changes or additions you make to your kidney care.

## Thank You to Our Speakers and Sponsors!

We are most grateful to the many people who made this BAAKP presentation possible. First of all, to our speakers Marianne Hutton and Jessica Goldman — this was a terrific educational event! Many said it was the best one yet! Thank you so much for your energy and time. And we wish also to express our appreciation to Fresenius Medical Care (Toni Hassard, RN, CNN, Regional Sales Manager, Northern California) for their generous donation to support the education of our audience. We are also appreciative of Whole Foods in Palo Alto for the donation of the Aram sandwiches. The gift baskets for the speakers were donated by Trader Joe's in Palo Alto (Town & Country Village), Charlie Kitz, Manager. And last, but not least, our unending thanks to the Palo Alto Medical Foundation and Becky Beacom for allowing us the continued use of their superb facilities. The BAAKP is indeed most fortunate to have such widespread community partners; we are indeed indebted to all of them.

Marianne Hutton, RD, CSR, CDE Finely Fit Nutrition Services www.finelyfitnutrition.com http://mhutton.mydiabeteseducator.org (707) 322-9821

#### Jessica Goldman

"Sodium Girl" blog http://sodiumgirl.wordpress.com/

Other Local Kidney Support Groups & Meetings			
AAKP American Association of Kidney Patients	T.R.I.O Transplant Recipients International Organization	San Francisco Polycystic Kidney Foundation	The National Kidney Foundation of No. California &
AAKP is a national organization founded by kidney patients for kidney patients. Has many resources available including magazines and educa- tional events. For more info: www.aakp.org	Silicon Valley Chapter Generally meets on the 2nd Thursday of the month For dates and locations, call (650) 353-2169 or go to: www.bayareaTRIO.org	For general PKD information, call: 1-800-PKDCURE For information about local groups, go to: <u>www.pkdcure.org/</u> <u>sanfranciscochapter</u> For chapter specific questions, please send email to: <u>sanfranciscochapter@pkdcure.org</u>	No. Nevada Has many resources available and sponsors many events. For more info: <u>www.kidneynca.org</u> (415) 543-3303 National Kidney Foundation <u>www.kidney.org</u>

# Hiking Half Dome With a New Kidney!

This is the first in a series of articles showcasing kidney patients and their adventures. Our intent is to show that having kidney disease (whether you have CKD, are on dialysis, or have a transplant) does not mean your "fun" life is over. World cruises, strenuous hikes, running marathons, skydiving — almost anything is possible with the right attitude and preparation. If you would like to have your adventure published in our newsletter, please send an email to <u>info@baakp.org</u>.

On a hot day in the middle of June 2010, a kidney transplant recipient named Ryan and some of his buddies took up the challenge of hiking the prestigious Half Dome rock in Yosemite National Park. This hike is an 18.5 mile trek that takes around 10 hours round trip.

Ryan had his transplant in October of 2006 where he received a kidney from a live donor—his Mother. Because of his poor health before the transplant, Ryan had a longer than usual recovery to get back to feeling strong, upbeat, and energetic. Once he felt close to 100 percent, he was ready to tackle the challenge and training for a hike at such a strenuous hike. Knowing that he would have a harder

time than his friends because of the effect his medication would have on his endurance level, Ryan trained for 7 months to get in the best shape possible. He even had his father join him in the training and eventual hike of Half Dome.

The morning of the hike, the guys (there were 5 of them) woke up at dawn, assembled their gear, and headed off toward the trail to begin what would turn out to be a very exciting day. The hike to the top (8,000ft. elevation) wasn't too bad on their legs and lungs. The training prior to the hike certainly prepared Ryan well. The view was spectacular and the wildlife really was awesome. As the guvs came closer to reaching the top of the rock, there was still snow on the steps carved out of Sub Dome, even though it was June. That made the walking much more diffi-

cult and dangerous. Sadly when they reached the top of Sub Dome, they realized that the cables needed to climb the face of Half Dome had not yet

Page 4

been installed (they were only 425 feet from the top). The Park Service decided to postpone installation of the cables because of all the late snow and the increased danger factor. Pretty bummed, Ryan and his team took a lunch break and then headed back down the trail.

Heading down the trail became a bit more exciting because the team somehow veered off the trail and became lost in the woods. When they noticed quite a few fresh bear droppings, they knew that they needed to be very alert and find the trail fast. Fortunately, after an hour or two of wandering and strategizing, they found the trail and continued their decent for the final hours of the trek. The last two hours were very tough because they had to walk down about 1,000 steps. Once they arrived in camp, they were jovial to say the least, and had a big feast at the lodge to celebrate their accomplishment.

Ryan mentioned several times that one of his prime motivations for hiking Half Dome was to show other kidney patients that no matter what your age, you can achieve things you once thought were possibly lost forever.



*Ryan (crouching) and his friends during their trip to hike Half Dome.* 

# The BAAKP Needs YOUR Help

The BAAKP has been in existence for more than 4 years now, working to educate, advocate and support those with kidney disease in the SF Bay Area. Most of the original Steering Committee members are still with the group; however, we have had some attrition over that time, and we are seeking people who are passionate about helping others in our local kidney community by joining the BAAKP's Steering Committee. We need help of all types, but more specifically in the graphic design, fund raising, and newsletter editing departments.

The Steering Committee is a great group of people who meet once a month (except for July and August), share a pot-luck dinner, share conversations and work to coordinate our endeavors.

If you feel passionate about helping others and having a good time while helping, please contact us with your contact information.



# Did you know...?

People in the early stages of CKD may be able to make their kidneys last longer by taking certain steps:

- See your doctor regularly.
- People who have diabetes should watch their blood glucose levels closely.
- People with reduced renal function should avoid pain pills that may make their kidney disease worse. Check with your health care provider before taking any medicine.

Source: <u>National Kidney & Urologic Diseases Infor-</u> mation Clearing House

# BAAKP to Begin Support Group Meetings

In an effort to further support kidney patients, BAAKP will start holding support group meetings on the 3rd Sunday of the month in the months when we do not have an educational presentation. Meetings will take place at the Palo Alto Medical Foundation at 1:00 pm and last no later than 3:00 pm. (This is the same facility where we hold our educational presentations — just a different room.) Both kidney patients and their friends and family are welcome to attend. No reservation is necessary — just show up!

We will continue to have our educational presentations and to publish this newsletter.

All events will take place at the Palo Alto Medical Foundation, 795 El Camino Real, Palo Alto, CA 94301. For more information about any of these events, contact **info@baakp.org** or call (650) 323-2225.



## Home Care Assistance Has Expertly Trained CaregiversTo Help Our Clients Live Better

- Peace of Mind. Our double screened well-trained caregivers can assist any time of the day or night.
- We Wrote The Book. In our new book *Hospitalization to Home Care*, we include a chapter on kidney patient care. Our experts also wrote both the *Handbook for Live-In Care* and *Happy to 102*, available on Amazon.com.
- Dietary Training. We provide training to our caregivers so they can prepare renal-friendly meals for our clients.
- Insured. Bonded, covered by workers compensation, insured and trained in our exclusive Balanced Care Method™.
- **Transportation.** Our caregivers are available any time of the day or night to assist with transportation for our clients.



Call for a FREE Consultations: 650-462-6900 www.HomeCareAssistance.com

Danville • San Jose • Oakland/Berkeley • Palo Alto • San Francisco

Volume 4, Issue 4

Page 5



# *Educating and Supporting Bay Area Kidney Patients*

Post Office Box 2332 Menlo Park, CA 94026-2332

Phone: (650) 323-2225 Fax: (650) 327-0178 Email: info@baakp.org

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

Winner of the 2010 Best Kidney Patient Support Group Award from AAKP

## SAVE THESE DATES!

- Educational Presentations September 18, 2011
- In-Center Hemodialysis
  January 22, 2012
- The California Transplant Donor Network
- May 20, 2012 To Be Announced

Support Group Meetings

- October 16, 2011
- November 20, 2011
- February 26, 2012
- March 18, 2012
- April 15, 2012

## Steering Committee Meetings Second Wednesday of every month at 6:00 pm

If you would like to join us in the leadership of this group, we would love to have your help. (Call for location) <u>info@baakp.org</u> (650)323-2225

# September 18, 2011 Meeting to Feature the Experts From DaVita Dialysis and Dr. Robert Tseng

The BAAKP looks forward to our guest speakers for our educational meeting on September 18, 2011. Dr. Robert Tseng from West Bay Nephrology will be accompanied by dialysis specialists from DaVita Medical. They will be discussing the many facets of clinic-based hemodialysis (in-center dialysis). From the history of dialysis to the present day science of kidney-replacement therapies, we will learn the details that we all seek. Bring your questions as now is the time to get them answered by the experts.



The event will be held on Sunday, Sep-

tember 18, 2011, starting at 1 pm at the Palo Alto Medical Foundation, 3rd Floor Hearst Conference Center, located at 795 El Camino Real, Palo Alto, CA 94301. Please stay for the social hour with refreshments and an opportunity to meet the speakers personally.

To register for this event, email us at **info@baakp.org**, call us at (650) 323-2225, or fax us at (650) 327-0178. You can also mail your reservation to BAAKP, PO Box 2332, Menlo Park, CA 94026-2332