



## A Kidney Transplant at Age 78? My Story! by Jerome Strom

In November 2002, after a routine physical examination, my doctor told me that I had the signs of early stage kidney disease. I did not ingest that statement other than to say, "What does that mean?" In typical doctor-speak; he said, "your kidneys are diseased; it is early in its progression."

With that short answer, I paid no attention to "kidney disease." My life went on without further concern. My business occupied my time and for exercise I was a three times a week tennis player, I was doing just fine. As I think back today, I was not playing as well as I had been, and I was getting tired before the end of the session. Also, my wife had a terminal illness: all my attention was to her and not to kidney disease.

In April 2006, I had a severe attack of itching all over my body. I used several different "over the counter" creams, but to no avail. I then asked for an appointment with my doctor, after his examination he suggested that I see a nephrologist. At an appointment with Dr. Feldman of Kaiser in Redwood City, he told me that my kidneys were severely diseased. I was told to consider either dialysis or a transplant. He then suggested that I should visit the dialysis center to see the process. Visiting the dialysis center with his nurse, I said to her, "I don't ever want to go through this process."

Dr. Feldman then suggested I meet with the transplant department at University of California San Francisco. They said that the waiting time for a kidney was six years. The exam did reveal that my health, other than the kidney disease, was good for someone my age. I was then advised to meet with a dietitian. I was told to follow a low protein, low salt, and low potassium diet to give myself as much time as possible, hoping of course, to



get by during my six-year waiting period.

During the waiting period, I had my blood tested every month; my creatinine and potassium, as well as my GFR, were monitored, along with several other

tests. In the meantime, Dr. Lin became my primary nephrologist. Like Dr. Feldman, she called me with my test numbers every month. In August 2012, my six years of wait time had gone by and Dr. Lin, in her usual concerned manner contacted UCSF to schedule another appointment.

During the interview at UCSF, I met two nephrologists. Both told me that I could wait for possibly two more years because while not good, my numbers were stable. I elected to take their advice after both doctors reassured me that I would remain at the top of their active list. I went away satisfied that I was not in immediate danger. I was asked to send a sample each time I had a blood draw, UCSF covered the FedEx mailing costs.

In August 2014, my test numbers declined further, my creatinine was above 5 and my GFR was 12. Dr. Lin called her contacts at UCSF, and I was scheduled for an appointment the following week. I was again told that I was at the top of their active list. Several tests were then conducted through September, October and November. I was assured that when they had an available healthy kidney that matched my blood type I would be notified.

Another doctor who worked in the nephrology department told me that it was their policy not to recommend a person who was over eighty years (80) of age for a

(Continued on page 4)

### The Bay Area Association of Kidney Patients

is a volunteer non-profit,

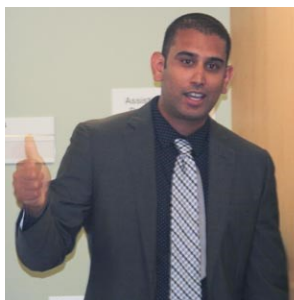
501(c) 3 organization with the

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 interactive social website at [www.baakp.org](http://www.baakp.org)

## Pearls of Knowledge for Kidney Patients by Matt Reeder

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Dr. Hussain Gilani of Chabot Nephrology Medical Group, Oakland, joined us in Oakland on September 20, 2015, for our 29th Educational Presentation. He received his medical degree from Baylor College of Medicine, then became a Nephrology Fellow at Emory

University.

He was drawn to kidney medicine where he could help patients make lifesaving changes since public understanding of kidney disease is lacking. In his research at Emory University, he studied the effect of lowering the blood pressure at night while a kidney patient sleeps; now he recommends that his patients take one of the prescribed blood pressure pills at night to protect their heart and brain.

In this presentation, he gifted us with many “pearls of knowledge” that patients and their family members should know about kidney disease. Dr. Gilani finds great satisfaction making a difference in how patients make their health decisions, and he thanked the Bay Area Association of Kidney Patients for the immense support provided to kidney patients.

The kidneys perform many vital functions for the body. First, they remove byproducts and toxins from the blood. However, the kidneys also regulate bone strength, anemia levels, hormone levels, and manage acid removal and blood pressure.

In the U.S., diabetes and high blood pressure cause the most cases of kidney disease. Individual racial groups suffer differing causes of kidney disease. For example, *focal segmental glomerulosclerosis* causes more kidney disease in African Americans due to genetic factors. Dr. Gilani hopes to stop the progression of this disease and possibly reverse the damage that has occurred.

The earlier your nephrologist can see you and finds the actual cause of your kidney disease, the more of your kidney function can be preserved, and your long-term health improved. Once chronic kidney disease reaches the stage of damage, shrinking, and scarring-- then the harm cannot be reversed. Sometimes the stage of disease can be determined just by blood tests. Other cases may require a kidney ultrasound or biopsy. Here are Dr. Gilani’s tips for the newly diagnosed and, indeed, all kidney patients.

1. **Blood pressure** as a kidney patient should

average 130/80 for the least amount of risk. You should have a blood pressure cuff at home. Keep a daily record that you can show to your kidney doctor, so that s/he can have an accurate picture of your blood pressure.

2. **Know and follow your lab results** by keeping a regular record of:

- ✓ **Creatinine**
- ✓ **eGFR (Glomerular Filtration Rate)**
- ✓ **Potassium**
- ✓ **Bicarbonate/Carbon dioxide**
- ✓ **Phosphorus**
- ✓ **Urea and KT/V**

3. **Exercise** reduces progression of kidney disease and lowers blood pressure. As little as two minutes of walking every hour through the day (about 30 minutes total per day) reduces obesity levels and improves blood pressure. Focus on cardiovascular exercises like walking (that raise your heart rate) and weight-bearing exercises that build muscle mass like squats and lunges. Resistance bands conveniently provide weight-bearing type exercises. Building muscle mass helps with insulin resistance, helps efficiently lose fat, and helps to build bone strength and prevent osteoporosis.

4. **Plan ahead.** Some important health steps can take many months to coordinate most effectively with your kidney doctor. If you can seek the help of a kidney doctor early enough, the disease can be stopped or reversed, preventing the need for dialysis. Likewise, if you can anticipate when you will need a transplant, planning ahead for the operation will be a greater benefit to you because kidney transplants without transitioning to dialysis yield better results for patients than those performed after the patient has begun dialysis. However, do not avoid dialysis, if it is needed, to preserve your health.

5. **"ACE inhibitor"** medication generally can help to keep kidney patients off dialysis for a longer time. ACE inhibitors act on the kidneys such that the microscopic filters inside the kidneys do not have to work as hard; but these medicines can also increase potassium levels, harmful to kidney patients. To plan ahead for taking ACE inhibitors, your kidney doctor should help you transition to a low potassium diet at the correct time.

6. **Educate yourself** through the web <http://>

[chabotnephrology.com/links/patient-education/](http://chabotnephrology.com/links/patient-education/), and through books available at Chabot Nephrology Medical Group. Local **education** and **support groups** such as those offered by the Bay Area Association of Kidney Patients ([www.baakp.org](http://www.baakp.org)) are invaluable to patients because these help patients mentor one another beyond a level of support that kidney doctors cannot provide.



### 7. **Accept diet changes:**

- ✓ **Avoid salt.** Eat less than 2 grams of salt per day. Salt is hard to avoid. There is much salt in restaurant food; avoid it if you can, or ask that your food be prepared salt-free.
  - ✓ Address the cause of your kidney disease through your **renal diet**. For example, if the cause of your renal disease has been obesity, adopt a diet that will help you get and stay lean. Eat healthy fruits and vegetables and avoid high salt & high fat restaurant food. Seek out a referral to a nutritionist; you are entitled to consult a renal dietician if you have chronic kidney disease.
  - ✓ Learn how to have the correct level of **protein** in your diet.
  - ✓ **Avoid all herbal supplements** because they can contain potassium, phosphorus, and unknown toxins, which are particularly unsafe for a kidney patient.
  - ✓ Pay careful attention to **phosphorus** content in your renal diet.
8. **Avoid NSAID medicines** like Motrin, Advil, and Aleve. It is critical to tell any doctor that since you are a kidney patient, you should **not** be taking NSAID's (Nonsteroidal Anti-inflammatory Drugs) as pain medications.
9. **Do not smoke** cigarettes.
10. Keep your **BMI (body mass index)** below 27. (See <http://www.sutterhealth.org/weight-management/bmi-calculator.html> )
11. **Be honest with your kidney doctor** and describe what sensations and feelings you experience, so that s/he can help tease out the clues that will show your present disease stage. Some important warning signs may appear in your laboratory tests, but others such as a decreased appetite, loss of muscle, feeling weak,

and strange metal taste to your food are signs that only you would know.

12. Kidney doctors and nurses prefer that their loved ones, if faced with kidney disease, avoid dialysis by having a preemptive living donor transplant, which is one that takes place before dialysis is needed. If dialysis becomes necessary, kidney professionals **prefer home hemodialysis or peritoneal dialysis** ("belly dialysis") because these therapies give the best health outcomes (due to more frequent treatments). Patients who receive dialysis only three times per week experience poorer health than those patients who receive frequent or daily dialysis treatment at home. Regular home dialysis treats a patient with results almost as good as a transplant. Daily home dialysis allows you to "be yourself" because you are not constantly recovering. However, he lamented that home dialysis treatments are not used as much as they should.
13. **Never be afraid to ask someone if s/he will be your living kidney donor.** You would be very surprised who would be willing to provide one of their kidneys. Don't feel guilty for accepting a donor's kidney because medical studies have shown that those donors who pass transplant center health screenings maintain good kidney health after donation.
14. Receiving a diagnosis of a severe chronic health condition causes you to feel grief and loss. **Do not get stuck** in denial of the actual condition you are facing; while you are taking time denying it, your kidney disease will likely continue to worsen. Accept your fear, **have hope**, and take steps to improve your health.

**Thank you Dr. Gilani for your time and talents!**

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## My Story! (continued from page 1)

transplant. In my case, I would be turning seventy-nine (79) in March 2015; very close to that age limit. Sadly, also at that time, a potential live donor was told that if he donated a kidney, his insurance would be cancelled. This was prior to the “The Affordable Care Act.”

On December 23, 2014, I received a call from UCSF and advised to standby. Later, after 9 p.m. I was called again; someone else had received that kidney. I was not disappointed by that second call because I knew now that I had not been overlooked. I knew then that I would remain on their active list.

It was 11:15 pm on January 27, 2015, when I received “**The Call**” and was told to be at the hospital within two hours. At first, they couldn’t find me, but they had my new wife’s phone number and she took the call. I received my new kidney the next morning. Thanks to the first-class medical care I received from Kaiser and UCSF, I am a happy kidney recipient!



**Dr. Gilani  
and Ms. Liu  
spoke to a  
full house at  
Alta Bates  
on September  
20th!**

**BAAKP** would like to extend a special **THANKS** to **Satellite Healthcare, Inc.** for sponsoring our Fall Educational Presentation!

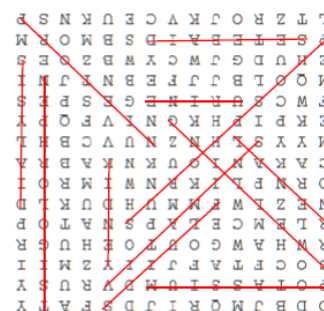


## Kidney Disease Word Search

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

DIABETES  
DIALYSIS  
FLUIDS  
KIDNEY  
NEPHROLOGIST  
PHOSPHORUS  
POTASSIUM  
PROTEIN  
RENAL  
SWELLING  
URINE  
VITAMINS

Don't peek!



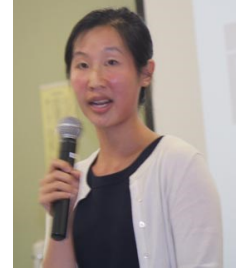
Solution

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# TAKE CHARGE OF YOUR RENAL NUTRITION by Matt Reeder

We extend very special thanks to **Clare Liu**, board-certified **renal dietitian** from Satellite Healthcare, Inc., who joined our September 2015 East Bay Educational event saying:

**What you eat can help you control the build-up of waste products and improve how you feel at every stage of kidney disease.**



She gave an inspiring, power-packed nutrition course — we encourage our members to review her entire talk at [www.baakp.org/video/](http://www.baakp.org/video/).

She emphasized that these highlighted nutrition guidelines should be reviewed based on your lab results, stage of kidney disease, and what treatments you receive. Ask for a monthly nutritional review of your renal diet based on your monthly lab results. And by exercising and losing weight, a pre-dialysis patient can **INCREASE** their GFR and slow the onset of disease.

1. You need **daily calorie intake** amounts based on your weight:
  - ✓ For chronic kidney disease patients or hemodialysis patients, each day you should take 15 food calories per pound of your weight. (For a hemodialysis patient who weighs 150 pounds, this equals 15 calories times 150 pounds, or 2250 calories per day.)
  - ✓ For peritoneal dialysis patients, the daily intake should be adjusted down slightly due to the sugar you absorb from your peritoneal dialysis solution.
  - ✓ After transplant, many patients need less calories because the transplant medications can cause weight gain.
2. **Daily Protein intake** should be:
  - ✓ Limited for pre-dialysis kidney patients, only about 0.3-0.4 grams of protein per pound of body weight.
  - ✓ Hemodialysis- and Peritoneal-dialysis patients should take *at least* 0.6 grams of protein per pound of body weight because dialysis removes protein from your body.
  - ✓ Patients early after transplant surgery should take 0.6-0.9 grams of protein per pound of body weight.
  - ✓ Transplant patients after recovery need 0.4-0.5 grams of protein per pound of body weight.
  - ✓ Plant-based protein intake should be individualized based on your potassium and phosphorus lab

Food item	Amount of Protein
1 egg	6.3 grams
1/2 cup tofu	10 grams
1 ounce meat, fish, or poultry	7 grams

results.

3. **Daily Fluid intake** for in-center hemodialysis patients must be carefully managed based on urine output. "Fluid" means: water, any beverage, ice cream, sherbet, popsicles, soup, gravy, gelatin, or ice.

For in-center hemodialysis patients, get help to find out your daily fluid restriction, or how much fluid you can take per day, then fill a pitcher with that amount of water at the beginning of each day. Only take fluid from that pitcher and when the pitcher empties, you may have no more fluid that day. (Remember to discard one cup from the pitcher if you drink one cup of juice, for example.) Home peritoneal dialysis patients generally can manage fluid intake more easily because of the daily treatment. Pre-dialysis and transplant patients generally have no fluid restrictions.



4. Sodium or **salt intake** increases your thirst, which will then make you take more fluid, which will then cause swelling because salt causes fluid retention. This can

(Continued on page 6)

## RENAL NUTRITION (continued from page 5)

overwhelm and damage your heart and lungs. This is why **2000 mg limit** of salt per day is critical especially for in-center hemodialysis patients. Many salt substitutes are made from potassium which can also cause problems. Sea salt does not differ nutritionally from regular salt.

Tips for limiting sodium/salt intake:

- ✓ Eat fresh fruits and vegetables
- ✓ prepare your own fresh food rather than eating out
- ✓ always determine sodium content of every menu item, referring to nutrition information label if possible
- ✓ Frozen vegetables (without sauces) generally have less sodium than canned vegetables.

Adapt your taste to a lower sodium diet by **committing** yourself to less than 2000 mg of daily sodium intake

AVOID THESE -- VERY HIGH SALT LEVELS:				
canned foods	canned soups	canned vegetables	condiments	soy sauce
saucers	dressings	pickles	olives	deli meats
cured meats	frozen meals	fast food	ketchup	mustard

FOR 2 MONTHS. After that time you will find that your salt craving will go away and you will naturally prefer less salt in your food.

5. **Daily Potassium** levels must be maintained at the correct level based on your lab results.

- ✓ In-center hemodialysis patients generally should restrict potassium intake to 2000-3000 milligrams per day.
- ✓ Peritoneal patients should restrict potassium intake to 3000-4000 milligrams per day.

Refer to a renal diet book for high- and low-potassium foods for your menus and recipes. Potassium consumption should be adjusted based on your lab results.

6. **Phosphorus** management for dialysis patients is challenging. Poor phosphorus management can cause heart disease and weakened bones which can be painful. Avoid foods like fast foods, cola drinks, sports drinks, iced teas, and packaged foods because these contain high levels of inorganic phosphorus which the body absorbs too quickly. This fast uptake of inorganic phosphorus make it difficult for the dialysis patient to manage correct phosphorus levels. Read the ingredient labels of all packaged foods and avoid anything that contains added phosphorus. To aid in phosphorus management, your doctor will likely prescribe or recommend a **phosphorus binder** medication based on your lab results.
7. **Calcium** for kidney disease patients needs proper management based on your dialysis treatment, your diet, your phosphorus binders, your lab results, and your medications.
8. You should ask your kidney doctor about a **renal vitamin supplement**, some of which may contain Vitamin B complex and Vitamin C. Over-the-counter vitamins may contain high amounts of potassium.
9. **Avoid all herbal supplements** since kidney patients can be sensitive to what you take into your body and the contents of many herbal supplements are not known. Also some herbal supplements have been reported to cause harm to kidney patients.
10. Finally, Ms. Liu urges you to always **study the food labels** so you can learn how to choose good foods and even teach your friends and family how to do this. Eat foods with fewer ingredients. Control your blood sugar by eating consistent, portioned meals, and by, for example, eating an apple instead of drinking a cup of apple juice. You should care about your diet more than anybody, so do not be afraid to ask questions, and make good food choices and purchases. Be active and move your body!

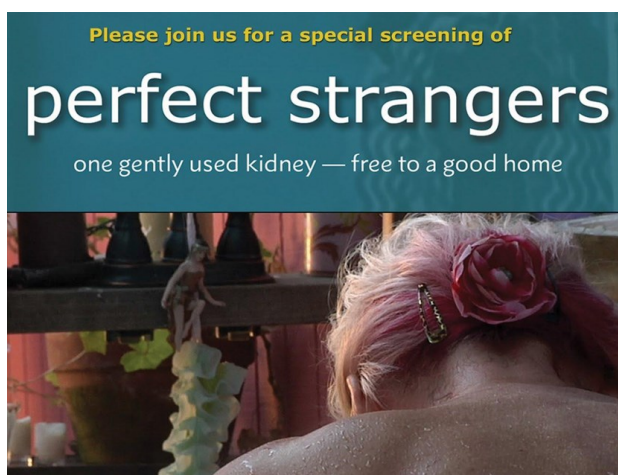


**Contact Info for Clare Liu, MS RD CSR:**

liucc@satellitehealth.com

510-383-9602

## Save the Date — Donor Sabbath Movie Time!



Sunday November 15, 2015 (12-3 pm)

at Trinity Hall,

330 Ravenswood Ave., Menlo Park, CA 94025

Free Refreshments and Door Prizes

Sponsored by the BAAKP and Trinity Church

### Movie Time! November 15, 2015

On Donor Sabbath weekend, we honor our living and deceased kidney donors and are fortunate to view this award-winning movie

### **What motivates an individual towards an extreme act of compassion?**

Ellie is determined to give away one of her kidneys. And 500 miles away, Kathy endures nightly dialysis and is losing hope of ever receiving a transplant—until Ellie reads her profile on an online website. Both women face unexpected challenges as their parallel stories unfold.



Scan to register

Register at [www.baakp.org](http://www.baakp.org)

or call 650-323-2225

Free Babysitting Available-call 650-326-2083

## BAAKP is again selected to participate in #GivingTuesday!

We have a day for giving thanks. We have two for getting deals. Now, we have #GivingTuesday, a global day dedicated to giving back.

On Tuesday, December 1, 2015, charities, families, businesses, community centers, and students around the world will come together for one common purpose: to celebrate generosity and to give.

The Palo Alto Medical Foundation is providing a \$3000 match for donations received by BAAKP for #GivingTuesday. So, for every dollar you donate, PAMF will donate another dollar!



BAAKP will contact you by email on December 1, 2015 or you may visit our website at [www.baakp.org](http://www.baakp.org). We hope you will participate in this world-wide event!



If you wish to donate prior to December 1st, please mail your check to:

Bay Area Association of Kidney Patients

P.O. Box 2332

Menlo Park, CA 94026-2332





# Bay Area Association of Kidney Patients

Post Office Box 2332  
Menlo Park, CA 94026-2332

Phone: (650) 323-2225  
Email: [info@baakp.org](mailto:info@baakp.org)

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

Please visit our website at  
[www.baakp.org](http://www.baakp.org)  
to make a donation, see back is-  
sues of our newsletters, and view  
videos of our past meetings. Your  
help is greatly appreciated!

This newsletter is not intend-  
ed to take the place of person-  
al medical advice, which  
should be obtained directly  
from your Doctor.



## ***SAVE THESE DATES !***

### ***Peninsula Events***

Trinity Hall, 330 Ravenswood Ave,  
Menlo Park, CA 94025

*Donor Sabbath Movie, -Perfect Strangers*

- **November 15, 2015, 12-3 pm**

**Palo Alto Medical Foundation-3rd Floor**  
795 El Camino Real, Palo Alto, CA 94301  
**Educational Presentation (1-4 pm)**

- **January 31, 2016**
- **May 22, 2016**

**Support Group Meetings (1-3 pm)**

- **January 10, 2016**
- **March 13, 2016**
- **May 1, 2016**

### ***East Bay Events***

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

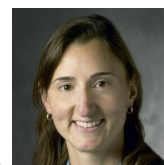
**Support Group Meetings (1-3 pm)**

- **November 8, 2015**
- **February 7, 2016**
- **April 10, 2016**
- **June 5, 2016**

## **Coming in January 2016!**

### **Stanford Kidney Transplant and Medicare/Medi-Cal**

Don't miss the January 31, 2016 Educational Presentation. Our guest speakers are from the **Stanford Kidney and Kidney/Pancreas Transplant Department**. We will hear from **Amy Gallo, M.D.**, Transplant Surgeon and **Colin Lenihan, M.D.**, Transplant Nephrologist. Among the details they will reveal: how to apply for a transplant, the wait list, as well as living and deceased donors.



On that same day we will also welcome from the Law Offices of Roy W. Litherland, **Dedra Jize, O.T., CSA**, who will bring updates on **Medicare and Medi-Cal** for all of us! Learn about the special benefits for kidney patients.

Please join us on **Sunday, January 31, 2016 from 1-4 pm** for this **FREE** event to be held at Palo Alto Medical Foundation, 795 El Camino Real, Palo Alto, CA 94031. Reserve your seat online at [www.baakp.org](http://www.baakp.org), call 650-323-2225 or scan this QR code to register. Refreshments and door prizes too!

**Generously  
supported by  
Astellas Pharma**



Scan to register