

Volume 9, Issue 3

Summer 2016



Bay Area Association of  
**Kidney Patients**

# Kidney Konnections

## How Compliance, Self-Advocacy and Knowledge led to Transplant My Story! by Greg Mustard

I have had HIV disease since the mid-1990's. With quarterly doctor visits, lab work, and combination HIV drug therapy, I've had no opportunistic infections; my CD4 count is good and viral load undetectable.

However, I have had high blood pressure and been on a low dose BP medication for a more than a decade. In 2012, after my physician noticed some abnormal labs, he referred me to a nephrologist who diagnosed Stage 2 kidney disease. He advised me to lose weight, reduce my sodium intake and prescribed additional medications. There didn't seem to be a sense of urgency; he said that the disease could take many years to progress. He believed the causes were high blood pressure and possibly inherited predisposition. (My mother also had high blood pressure and eventual kidney failure.)

I tried to reduce the sodium in my diet and to lose weight, with marginal results. Medications were frequently changed to no avail. My GFR continued to worsen.

In the spring of 2014, I changed jobs, insurance, and doctors and my new nephrologist told me that I was now at Stage 3. Two months later I wound up in the ER with a TIA (mini stroke). While a TIA was never confirmed, my nephrologist was called in and advised that I had ESRD and that I must prepare to go on dialysis. After an orientation class where a doctor discussed the different dialysis options, I elected to go on Peritoneal Dialysis (PD). With PD I would be able to



maintain a somewhat normal life and continue working and traveling. I also thought it would be physically

easier on my body and a good entry point to dialysis. I remembered that my mother had a difficult life on hemodialysis, and it took almost a full day for her to recover. Her diet and fluid intake were very restricted, and I did not want that for myself.

I was placed on a very strict renal diet, and PD catheter surgery was scheduled. After surgery and a five-week recovery and training period, I started PD. My pre-dialysis diet eased, and I could now have some red meats and small amounts of the high potassium foods that we all love to eat (potatoes, tomatoes, and beans). Dairy was still off limits, but because I still had some kidney function and my urine output was good, I did not have to be so concerned with limiting my fluid intake.

The challenging aspect of PD was establishing my routine and maintaining compliance, the diet or the medications. For example, PD takes about 8 hours to complete every night, so you need be very aware of the clock. My work day started at 7:30 am so I had to hook up to the overnight cyclor machine at about 8:30 pm.

(Continued on page 2)

## 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)



In September 2014 I had my evaluation for a kidney transplant at UCSF and was put on their waiting list. At that time, they had over 5000 on the list and the average wait time was between 5 and 7 years.

I joined the Bay Area Association of Kidney Patients (BAAKP)

attending their support group meetings and educational seminars. In May 2015 there was a presentation about kidney transplantation; the presenter showed all of the transplant centers in Northern California and their statistics. UC Davis is in a different OPO (Organ Procurement Organization) network than UCSF and performed a similar number of transplants per year, but the UC Davis waiting list was significantly shorter. I decided to apply to be on their list too and increase my odds of getting a transplant.

During my next dialysis clinic visit, I asked my doctor about also referring me to UC Davis. He stated I could not apply because they did not accept HIV patients. Devastated and a little skeptical because I knew HIV patients were getting transplants elsewhere, I decided to inquire. I called the next morning and was told that yes, they did accept HIV patients, and since I had already been accepted by UCSF, I could use many of the same test results, but I would pay for the evaluation and any additional testing. At a cost of around \$1000, I felt it was well worth the price if I could get my transplant faster.

I called my Dialysis Renal Case Manager and asked for a referral to Davis. She was surprised at the news, but would get started. During my next appointment at the dialysis clinic, my doctor was very apologetic about having the wrong information and pledged that the team would help in any way they could.

I applied to UC Davis, completed their labs, met with the transplant team and waited for the acceptance letter. I called them every two weeks to check in.

On February 26th at 9:00 am I got a call at work from a Transplant Coordinator from UC Davis saying they thought they might have a match for me and was I available. **YES!** I was in shock. I had still never been officially approved, and now they are calling! How could this be? I did not hear from

them the rest of the day. When I got home that afternoon, the acceptance letter was waiting in my mailbox. The letter was dated Feb 12th and stated that I was officially on their transplant list. I felt like I had won the kidney Lottery! I had been on the UC Davis list for only two weeks. I knew of people in my BAAKP Support Group, who have been waiting for years. I kept asking myself, "Why me?" That question remains to be answered.

By 5:00 pm, I called, and they were still waiting on word about the donor's kidney. At 11:45 pm I received "the call." I was to report to the hospital in Sacramento, 2 hours away, at 7 am. I did not get much sleep that night!

At the hospital the next day, there were more tests to confirm that I was still suitable and also that the donor's kidney was of high quality. Final go-ahead was given at 4:30 pm and I was in surgery by 5:00 pm. The surgery lasted 5 hours and everything went well. With some deceased donor kidneys, it can take a while to start working. Mine acted more like a live donor organ and started up immediately. The staff was elated by my daily labs and recovery, and I was sent home the fourth day after surgery.

After three months recovery at home, I am now back at work full time. There is still much hard work ahead. Compliance is even more important now, but I feel I have been preparing for this moment for the last twenty years. With much support from family and friends, I am the luckiest guy in the world!

Here is my take away to have a successful CKD journey:

**Compliance is crucial.** Be compliant in your dialysis schedule and routines. Stick to your diet and nutrition goals and monitor your labs carefully and make adjustments as necessary.

**You must advocate for yourself.** Be an active participant. Only you know what works best for you.

**Knowledge = Life.** Do your research, educate yourself and always ask lots of questions. Talk to your nurses; they are always a great resource. Consult with members of BAAKP ([www.baakp.org](http://www.baakp.org)).

**Yes, you can have HIV and get a transplant!**

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

## 7 Ways to Know if You Are Getting GOOD Dialysis



On May 22, 2016, we welcomed Dori Schatell, MS, special guest speaker for the **Charles & Joan Horngren Kidney Education Series**. Ms. Schatell is the Executive Director of the [Medical Education Institute](#), and

Co-Author of *“Help, I Need Dialysis! How to Have a Good Future with Kidney Disease”*.

Ms. Schatell reminds you that it is normal to be scared, depressed, or angry when first diagnosed with End Stage Renal Disease (ESRD). Dialysis is a life-changing event. Learn as much as you can.

The purpose of dialysis is to remove extra water and toxins from your body. In the short-term, the focus is on water, and the long-term concern is the toxins. Your lab tests show urea (blood urea nitrogen, or BUN), the protein waste that builds up in the blood. Your clinical care team will discuss urea at the monthly review of your lab results. Although it is used as an industry standard, it is not a good measure of how effective your dialysis is. Urea is tiny, rounded molecules that pass easily through the dialysis membrane (the filters or tubes you see in your dialyzer). The small size of these molecules makes it easier to clean the blood of these wastes.

But there are larger molecules, called middle molecules, which can cause long-term complications with arthritis, joint pain, and bone disease. One such middle molecule is beta-2-microglobulin. It is a larger and twisty molecule, preventing easy passage through the dialysis membrane pores.

*Kt/V* is a way of measuring dialysis “adequacy,” but *KT/V* does not measure water—it only measures urea. Some patients ask, “Why do I feel bad when my lab results are good?” A build-up of these middle molecules in your blood is probably the reason. Ms. Schatell said “The most meaningful measure of good dialysis is how you feel.”

Ms. Schatell conveyed that the job of good dialysis is to keep the body in balance, in homeostasis. Dialysis should keep all of the body’s chemistries

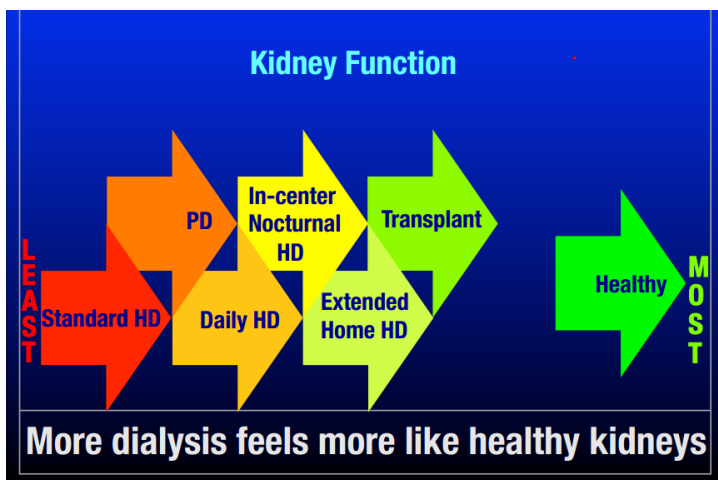
within a constant, tight range all the time. To get good dialysis, you must choose the type of dialysis that best fits your life. Many patients are not told they have *several* options. Those who choose self-care or home dialysis are engaged in their own care, [tend to feel](#) healthier, and ultimately to graduate to a successful kidney transplant.

1. **Standard In-Center Hemodialysis (HD):** the most common, but least efficient type, with the smallest dose of dialysis. There are 168 hours in a week, and this option only gives you three treatments of about 3.6 hours each. So, standard in-center HD requires the most limits on what you can eat or drink, the most medicines, and causes the most symptoms (sleep problems, lack of sex drive, cramps, headaches, etc.)
2. **Nocturnal In-Center HD:** It is much gentler than standard HD. You do treatments in a clinic three times a week, but they are at night for 8 hours—which is twice as much dialysis. People who use this option feel better, stay out of the hospital more, and live about twice as long as those who do standard in-center HD.
3. **Continuous Ambulatory Peritoneal Dialysis (CAPD):** CAPD is easy to learn and do. Both types of PD use the lining of the inner abdomen to clean your blood. A nurse teaches you to do 30 minute “exchanges” of dialysis fluid 3-4 times per day through a catheter (tube) placed in your belly by a surgeon. Between exchanges, dialysis fluid stays or “dwells” in your belly, so you dialyze all the time. PD is much gentler than Standard In-Center HD and does a better job of removing water—but is less efficient than HD for toxins.
4. **Continuous Cycling Peritoneal Dialysis (CCPD):** It is also gentler than standard HD, easy to learn, and done at night while you sleep. (Some people also need a daytime exchange to get enough treatment.) A nurse teaches you to use a machine, called a “cycler”, to fill and drain PD fluid into and out of your belly.
5. **Standard Home HD:** This is three times a week, like in-center—or every other day—for 4-5 hours. The machine for home HD is smaller than the in-center dialysis machine. A nurse teaches you how.

(Continued on page 4)



6. **Short Daily HD:** A nurse teaches you to do use a small HD machine to do 2-4 hour treatments, 5-6 days per week. People who use this option get to choose what time they want to do their treatments. Since dialysis is done nearly every day and is more efficient than PD, there are fewer diet and fluid limits. Blood pressure is better controlled. People feel better and live longer than they do with standard in-center HD.
7. **Night Home Hemodialysis:** A nurse teaches you to do your treatments 3-6 nights per week while you sleep. This is the *most* dialysis you can get, and survival is about the same as for a deceased donor transplant—3x longer than standard in-center HD. People feel good just 10 minutes after they get off the machine, and may have no diet or fluid limits. Most don't need blood pressure pills or phosphate binders.



### Effectiveness of various dialysis techniques

Ms. Schatell described the seven ways to know if you are getting good dialysis:

1. **You feel good right after getting dialysis.** The amount of time it takes to recover after your dialysis treatment is important. With peritoneal dialysis (PD), you generally feel well right away because it is gentle. In a study of thousands of patients, researchers found that about 1/3 felt good in less than 2 hours and 41% felt better within 2-4 hours. Those who took more than 7 hours to recover after treatment did not live as long. Quick recovery also decreases risk for hospitalization. The two reasons for long recovery time are (1) taking off too

much water and (2) taking water off too fast.

2. **Water is removed slowly and gently.** Blood vessels prefer a gentle flow. And your dialysis access does not like the turbulence (pressure) caused by “fire hose” dialysis. Taking off water too fast causes muscle cramps, blood pressure crashes, and a “washed out” feeling. It also causes tissue damage due to a lack of oxygen in the blood. This is called stunning, starving tissue of oxygen, causing heart damage. In myocardial stunning, the body repairs the heart by creating a patch (fibrosis) each time an event occurs. Fibrosis caused by stunning causes the heart to enlarge, which is the leading cause of death on dialysis. Your body is 60% water, but dialysis only reaches the blood, which has just 8% of total body water. Good dialysis takes *time* because water has to shift from inside cells, to between cells, and then into the blood vessels to be removed by dialysis, like a “waterfall.” The more time you spend on dialysis, the more water is removed from your body. Removal of water should be slow and steady, so the *rate* of *ultrafiltration* (pulling water out; UFR) is key. Dialysis should not remove more than 10 ml of water per hour per kilo of body weight. Medicare is looking at restricting UFR by dialysis centers to less than 13 ml of water per hour per kilo of body weight. Ms. Schatell provided an online tool to the audience for patients to calculate their ultrafiltration: [www.homedialysis.org/ufr-calculator](http://www.homedialysis.org/ufr-calculator). Cooler dialysate also helps prevent stunning; it should be about ½ degree centigrade cooler than body temperature.

3. **You don't need blood pressure medications (or need less).** The pill burden (how many pills you take) is higher on in-center HD than in any other disease, with an average of 19 pills per day, and these may have unknown, harmful interactions in your body. Types of dialysis impact the number of pills you may take. Those on PD take less medication at first, but the pill burden will increase as the treatment becomes less effective over time. Those on short daily HD or nocturnal in-center HD need far fewer

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## 7 Ways (continued from page 4)

medications. Home nocturnal HD patients may not need any blood pressure pills or phosphate binders..

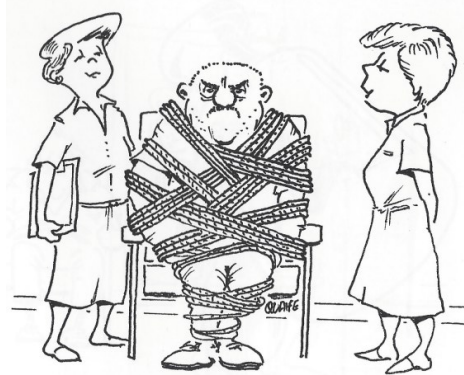
4. Calcium should only be where it belongs. This mineral belongs in our bones, teeth, and a tiny bit in the blood. It helps your blood to clot and your nerves to talk to your muscles. Calcium is present in foods, especially dairy but also leafy greens. When phosphorus and calcium levels are high, you can get harmful bone formation in the arteries (called calcification). Good dialysis helps maintain bone-mineral balance.
5. Fewer or no binders are needed. Phosphorus is in more food than calcium. It is added to processed food, along with potassium, and is absorbed 100% from processed foods. (Phosphorus from natural sources like beans, dairy, and meat, it is absorbed at a much lower rate.) The amount of phosphorus in the body increases with each meal, since standard in-center HD does not remove much, so binders are needed to try to help keep the levels safe. PD removes 10% more phosphorus than standard in-center HD. Those on short daily HD may need fewer binders, but must be monitored because patients who feel better eat more. Some patients on nocturnal home HD remove so much phosphorus, they need *supplements* instead of binders.
6. **Healthy Nerves.** If you have neuropathy and do not have diabetes, you may not be getting

enough dialysis. Neuropathy is common among dialysis patients, but poor dialysis is not the only cause.

7. **Sleep.** If you are having problems sleeping or feel restless, you may not be getting enough dialysis.

Ms. Schatell closed by giving a copy of her book, [\*Help, I Need Dialysis\*](#) to each family in the audience. To help you determine what type of dialysis best fits your life, there are other resources, including interactive tools and books. They can be accessed by smartphone or computer:

[www.mydialysischoice.org](http://www.mydialysischoice.org) and [www.kidneyschool.org](http://www.kidneyschool.org). She also shared that Home Dialysis Central [www.homedialysis.org](http://www.homedialysis.org) also has an active [Facebook Discussion Group](#) that you are welcome to join to learn more. “Good dialysis helps you feel well and do the things that are important to you in your life.”



Cartoon by Peter Quaife, a Canadian dialysis patient from his book [\*The Lighter Side of Dialysis, Volume 1\*](#) Copyright 2005 by Jazz Communications, Ltd.

**And this, Joyce is one of our more compliant patients**

## Patient Panel Discussion ~ Types of Dialysis Treatments

We were fortunate to have 5 patients relate their dialysis experiences. Our first panel member was Greg Mustard and his inspiring story is our patient cover story for this issue.

Horace Greeley's kidney disease started in his early 20's when he was advised of mild proteinuria. Because he was young and having way too much fun, he was not very concerned but did make some dietary changes. By 1990, he began having serious trouble controlling his blood pressure and



was diagnosed with IgA nephropathy. He was told he had about 5 years before he would need dialysis and in another 5-7 years he would die! He and his wife made a number of diet and lifestyle changes, and he delayed dialysis until January 2009. First, he began in-center hemodialysis and later transitioned to peritoneal dialysis (PD). In September 2009, he received a transplant from a fellow parishioner, which remained successful for almost 3 years and then returned to peritoneal dialysis. His take-away: “If you find your doctor moving you from 1.5% to 2.5% to 4.25% on your dialysate solution, it's time to get off PD and move to

(Continued on page 6)

## Patient Panel Discussion *Continued*

hemo.”, and later PD wasn’t working well any more. He began **standard in-center hemodialysis**. He then quickly converted to Nocturnal In-Center Hemodialysis--since then his labs have never been better and the nighttime schedule was OK for him. He encourages dialysis patients to educate themselves, ask questions, and do not rely solely on information provided by medical professionals.



Phil Wyche, who is a BAAKP board member and runs the support groups, shared his experience with dialysis next. He discovered he had kidney disease after a routine physical exam- his physician noted hypertension and his kidneys were starting to fail. Like

Horace, he was young, so the information “went in one ear and out the other.” Eventually, he began getting physically ill and went back to the doctor who said that the hypertension is causing kidney damage and prescribed BP medicines. Because he was young and physically fit, he did not take his medicine as prescribed. Then while playing softball, he felt ill and went back to the doctor. Within 4 hours of getting lab results, a catheter was placed in his chest. He is grateful for support from his family and mentions it is important when trying to adjust to dialysis. Phil did not want to do it and had an “attitude because of it.” He was on in-center hemodialysis for four years. He felt like it was a hindrance, something stopping him from doing the things he wanted. After becoming a member of the BAAKP, he switched to Peritoneal Dialysis-- he was able to do the things he did before dialysis and travel a lot. As a BAAKP member, he started going to the support groups regularly and soon became chairman, where he encouraged compliance, self-advocacy, and engagement with doctors. Then one day his wife suggested he might want to advocate for himself, just as he was advising other patients to do, and so he began! At this point, Phil was determined to get the answers he needed. He tried to reach his transplant center coordinating staff to advocate for his transplant and made many contacts. After a month of discussion with staff, he was ready for transplant. Two weeks later on Thanksgiving Day he got “the call.” No one else can do the work for you, you have to **push** because no one else will advocate for you.

Wayne Bennion shared that he was not aware of his kidney disease until he reached Stage IV. He was disgusted with his internist who referred him to a nephrologist after this



late stage diagnosis. He started home hemodialysis on May 4, 2015. Wayne’s situation is unusual because he does his home hemodialysis by himself, and he has never experienced any other type of dialysis. The process includes setting up his machine and allowing it to prime itself

while he prepares and lays out supplies. Once the machine is ready, he self-cannulates (places the needle in his arm). He dialyzes 3-4 hours per day, 5 times per week. His dialysis staff believes he has gained weight, but he questions this!



Lastly, Christie Chapman shared her story with kidney disease which started at the age of 15 due to Systemic Lupus Erythematosus (SLE). She, like Wayne, was not diagnosed until Stage IV. At age 18, the kidney disease worsened after going away to college. She returned home, where her doctor began chemotherapy to help slow the progression of the autoimmune disease. But, ten days after her ten year high school class reunion, she went into kidney failure. , Having worked in dialysis for four years, she already knew what dialysis treatment option she wanted. She trained one week and dialyzed at home on her own thereafter. She tried **Continuous Cycling Peritoneal Dialysis (CCPD)**, but it caused discomfort during the night as the machine emptied the fluid from her peritoneal cavity. She remained on **Continuous Ambulatory Peritoneal Dialysis (CAPD)**, manual dialysis, for three years. She walked around the dialysis center where she worked, hooked up to the IV pole as she dialyzed. As a result, she had the opportunity to educate hemodialysis patients, and several decided to change. She was very careful with handwashing and following sterile technique. As soon as Christie started dialysis, she reached out to the transplant center of Hermann Memorial Hospital in Houston, TX. She was on hold for one year to make sure her lupus was in remission. After another year and a half, she got “the call” and has had a successful transplant for 10 years now.





# National Convention Time!

## EXPLORE YOUR FUTURE TODAY

American Association of Kidney Patients  
National Kidney Patient Meeting  
Nashville, Tennessee  
September 23-25, 2016  
800-749-2257



"Lunch with the Experts"

- *Dialysis patient safety*
- *Living kidney donation*
- *Kidney friendly diets*
- *Innovations in treatments/medications*
- *Patient engagement*

[www.aakp.org](http://www.aakp.org)

[www.aakp.org/patient-meeting-registration.html](http://www.aakp.org/patient-meeting-registration.html)

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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.

*Other Kidney Resources – Check [www.baakp.org](http://www.baakp.org) for more!*

#### **American Association of Kidney Patients AAKP**

1440 Bruce B Downs Blvd  
Tampa, Florida 33613  
(800) 749-2257  
[www.aakp.org](http://www.aakp.org)

#### **San Francisco Polycystic Kidney Foundation 1-800-PKDCURE**

[www.pkdcure.org/  
sanfranciscochapter](http://www.pkdcure.org/sanfranciscochapter)  
[sanfranciscochapter@pkdcure.org](mailto:sanfranciscochapter@pkdcure.org)

#### **Transplant Recipients International Organization TRIO**

2nd Thursday of each month 7:30  
pm. El Camino Hospital, Conference  
Room G  
2500 Grant Road,  
Mountain View, CA  
(408) 353-2169  
[www.bayareatrio.org](http://www.bayareatrio.org)  
[www.trioweb.org](http://www.trioweb.org)

#### **The National Kidney Foundation**

131 Steuart St Ste 425  
San Francisco, CA 94105  
(888) 427-5653

[www.kidneyca.org](http://www.kidneyca.org)  
[www.kidney.org](http://www.kidney.org)



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to make a donation, see back is-  
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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)***

- July 10, 2016
- October 16, 2016
- January 8, 2017

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

Alta Bates Summit Hospital  
Merritt Pavilion 350 Hawthorne Ave, Oak-  
land, CA 94609  
(BART-MacArthur station )  
***Educational Presentation (1-4 pm)***

- September 11, 2016

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

- August 7, 2016
- November 6, 2016
- February 12, 2017

***Board of Directors' Meetings***

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

## Join us in Oakland on September 11, 2016 for **Financial, Legal and Insurance Advice**

A blue-ribbon panel of experts will join us on September 11, 2016 to help you sort out your **non-medical kidney problems**. These problems include costs, coverage, availability and roadblocks to treatment. Specialists from the fields of **dialysis, transplant, Medicare, commercial insurance and the legal world** will present how they can help the kidney patient deal with these dilemmas. Be prepared and bring your questions!



Please join us on Sunday, September 11, 2016, from 1-4 pm for this **FREE** event. It will be held in the Fir Room (1<sup>st</sup> floor) at Alta Bates Summit Medical Center, 350 Hawthorne Avenue, Oakland, CA 94609.



Scan to register

Reserve your seat online at <http://tinyurl.com/baakp-Sept2016> or at [www.baakp.org/events](http://www.baakp.org/events) or call 650-323-2225 or scan the QR code to register. Refreshments and door prizes too!

Thank you to our sponsor:

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**Reserve your seat now!**