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Fall 2017



Bay Area Association of
Kidney Patients

Kidney Konnections

"I Need A Kidney"—How a facebook post changed her life

Anne Langer, as a Medical Lab Scientist, worked in the Stanford Labs for many years and knew much about lab results and diseases. Her background was indeed fortunate, as her health would take her deeply into that world. It was Type I diabetes that struck first when she became sick at the age of 23. She lost her mother and shortly after that developed an excessive thirst, excessive urination, loss of weight and exhaustion. She was diagnosed with Type I diabetes, an auto-immune disease, which Anne believes was caused by the stress of her Mother's death.

She continued working but was feeling sick and eventually (mis)diagnosed with Multiple Sclerosis (MS.) She went on medical leave and was treated for MS with what she calls "horrible medications." By the end of 2007, her Primary Care Physician at Palo Alto Medical Foundation (PAMF) saw signs of kidney disease in her tests and referred her to Dr. Toby Gottheiner, a PAMF nephrologist. Anne stresses that the kidney disease was not related to her type I Diabetes, but to the autoimmune disease, called ANCA vasculitis, which was diagnosed after a biopsy. (Vasculitis is an inflammation of the blood vessels; there are many types).

Because of her experiences with diabetes, Anne always believed in advocating for yourself. She noticed a poster in the nephrology waiting room at PAMF advertising a Bay Area Association of Kidney Patients (BAAKP) meeting. She started attending the support groups and learned about diet and how to reduce phosphorus, and when and how to get on the kidney transplant list. Her kidneys limped along for seven years: she avoided dialysis by eating only 3 oz. of protein a day, "the size of a deck of cards," and cut out phosphorus-laden sodas.



Anne with her donor John

When grocery shopping, she "checked every food label for phosphorus and any ingredient that had the word phosphorus in it. For example, phosphoric acid, tri-calcium phosphate, etc. If it had 'phos' in it, it went back on the shelf!" ~

She worked to get listed for a Stanford transplant, and then at the encouragement of someone at a support group meeting, also registered at UC Davis. But, she knew that this couldn't go on; her kidneys were failing. And, thinking she would always get a transplant, Anne really hadn't prepared for dialysis.

At one of the BAAKP Educational Presentations, she heard a woman speak who had donated a kidney to her niece, resulting in a first-person book about the donation process (Belia Marina, A Gift Not Wasted). Anne began to see the possibilities of a living donor. (Since the first living donor transplant in 1954, there have been more than 50,000.) Anne now had renewed hope.

She started with a simple message on Facebook, posting a cute graphic such as this one with the words "If you are considering giving the gift of Life, please contact Stanford Living Donor Coordinator at 650.498.8382, and mention me. No obligation, you're just asking for info." She hoped that interested friends would call Stanford. And people did!

**ROSES ARE RED
KIDNEYS FILTER AND MAKE PEE**



A high school friend drove from LA for testing, but for some unknown reason, that fell through. (The transplant centers never tell

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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

you why.) Other people did call but, for some reason, did not progress to testing. Anne knew she needed a transplant soon, or she would have to start dialysis. Fortunately, her husband's insurance covered the costs of the tests on the possible donors and even transportation.

And then along came John. Anne reports that “John made it easy!” John is the husband of Diane, her best high school friend who now lives in Oak Harbor, on Whidbey Island, Washington. He is a retired Naval Aviator who had bravely flown airplanes on and off aircraft carriers and was physically very fit. He and his wife watched helplessly as Anne's kidneys deteriorated from the diabetes and autoimmune diseases. Diane had her blood tested, and it

wasn't a match, but John's was! And, after much testing at Stanford, John was approved as a donor. The surgery took place shortly afterward, with Dr. Stephan Busque at Stanford.

Immediately, Diane and John noticed that Anne looked better; the color had returned to her previously pale face. “She had this glow about her.” John said, “I would do it again if I had 3 kidneys.” Anne Langer says her hero John is that kind of guy and gave her confidence to proceed with the transplant. And, she just celebrated her 2-year “kidneyversary” in April.

Anne is grateful to have found the Bay Area Association of Kidney Patients and to learn about treatment options she had not considered. She encourages everyone to advocate for themselves and to learn as much as possible.

The Implantable Bio-Artificial Kidney with Dr. Shuvo Roy

Dr. Roy and his co-workers have potentially realized the biggest breakthrough in kidney disease since the invention of dialysis – a mechanical, manufactured, surgically-implanted, artificial kidney. This dream may be realized soon, within a few years. See The Kidney Project at kidney.ucsf.edu.

It was a special day on May 21, 2017, when Shuvo Roy, Ph.D., joined the Bay Area Association of Kidney Patients (BAAKP) for our 10th Anniversary Celebration. Over 130 patients, families, supporters, and professionals joined BAAKP to celebrate ten years of Educating and Supporting San Francisco Bay Area kidney patients. From Dr. Roy, we learned about the current state of kidney replacement. Dr. Roy is Technical Director of The Kidney Project, and Professor, Department of Bioengineering and Therapeutic Sciences, UCSF Schools of Pharmacy and Medicine. His last visit with us was about 3 years ago, and their research has progressed rapidly.

Today, there are currently over 2 million patients with ESRD (End Stage Renal Disease), and the numbers continue to grow. These numbers are growing for a variety of reasons, but the primary causes are hypertension (high blood pressure) and diabetes. In



1996, The number of ESRD patients was about 300,000, with the number of transplants performed that year at about 11,000. In 2013, the ESRD patient population had more than doubled to about 625,000, while the number of transplants performed only increased slightly to about 16,000. The clear trend over the last 20 years shows that there are just not enough organs to go around to all patients in need, and growth in kidney disease greatly outpaces the availability of donor organs. Those patients that receive a donor organ are very fortunate.

Look at medical devices developed for heart problems--tiny, precise defibrillators implanted inside the body providing an unprecedented quality of life. As a comparison, kidney dialysis has not evolved much since the late 60's which also happens to be the same time frame as the invention of the pacemaker. Why haven't we been able to do more? The technology is there. Shouldn't we demand more? Dr. Roy described some of the technological challenges to replace the complex jobs that the kidney does for our body by working on our blood.

The kidney performs many more functions than only filtering the blood, and dialysis was only designed to

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

perform filtering. Consequently, dialysis will never provide a natural quality of life because dialysis cannot replace the complex biological work on your blood that the healthy kidney performs. Kidney medical experts have known this for decades. Dialysis technology has not really changed since it was invented 50 years ago.

About ten years ago, Dr. H. David Humes, MD pioneered the concept for the basis of The Kidney Project's work. Dr. Humes showed that **cell therapy** provided a benefit to patients with kidney failure. He came up with a device he called RAD (Renal Assist Device), which, similar to a dialysis machine, pumped the blood through normal dialysis filtration, but also pumped the blood through a **bioreactor**. He tested it on patients with some success. The bioreactor contained specially grown kidney cells that were in contact with the patients' blood. This new two-part device tested in hospitals on intensive care patients began to show that a mechanical device could provide those biological functions similar to a real kidney.

Then, through the use of Silicon Nanotechnology, The Kidney Project designed a very thin plate that is a better design than traditional dialysis filtration because this silicon plate is similar to the blood filters in the natural kidney. By the use of silicon wafers, the team created a very thin membrane with long straight pores requiring very little energy to drive the filtration. Blood can be pushed through this new silicon filter with no pumps, unlike the old dialysis technology which requires very complicated and expensive pumps. Furthermore, with the use of

special coatings on these silicon plates, there will be no need for blood thinners that prevent blood clots and other issues.

These two major components, 1) a blood filter ("hemofilter") and, 2) a bio-reactor containing active living cells together perform filtration along with the gentle, natural, biological work on your blood, similar to that of a natural kidney.

What is possible?

Continuous treatment 24/7: avoiding the ups and downs associated with fluid overload or too much fluid removal.

Freedom of mobility:

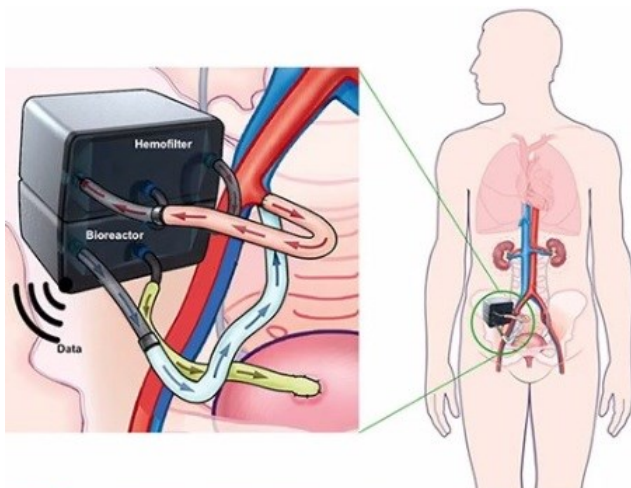
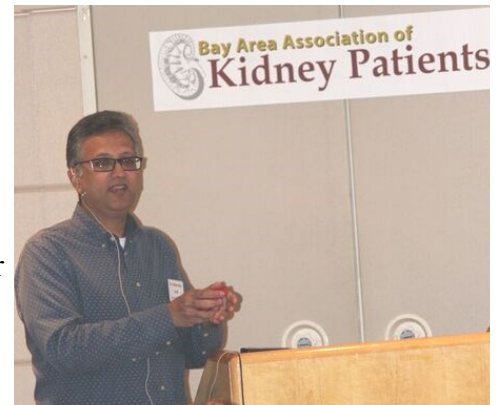
imagine going to Disneyland or on a cruise without being tethered to a machine. **Quality of life:** no catheters, no special dialysis diets, fluid restriction, or dialysate. The side effects are similar to any major surgery as the device will be surgically implanted.

Most importantly, this device, may prove better than a biological organ transplant because the patient will not require life-long immunosuppression drugs, all possible because the bio-reactor silicon chip keeps the body's immune system separated from these bio-reactor cells, while still allowing these cells to perform the natural biological kidney-like processing of blood.

How can we move this forward? Take a concept that was used in a hospital and make it available to the more than 500,000 patients in this country that are on dialysis and make this a reality? This is **The Kidney Project**.

The goal in the next few months is to begin clinical trials in real kidney patients to demonstrate basic safety. The Project hopes that full clinical testing will begin 1 to 2 years after that.

(Dr. Roy mentioned that other pioneering research could also help kidney patients. Perhaps, many years



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The Implantable Bio-Artificial Kidney (continued from page 3)

from now, biological factories may grow new, natural kidneys in a laboratory). We hope that The Kidney Project at UCSF will get the support it needs to provide a real and valuable advance in treatment within the very near future.

Search kidney.ucsf.edu, where you can access literature and the status of the project. There is also an active Facebook community at facebook.com/ArtificialKidney with currently

over 40,000 followers; it is the primary way of communicating their activities on a day to day basis. Be sure to stay in touch there to donate, sign up for clinical trials, or to learn how to help the Project receive the support it needs from our communities, investors, health care system, and government policies. We look forward to the day when this promising technology can deliver the dream of the best care for every kidney patient.

The Bay Area Association of Kidney Patients is celebrating our 10th Anniversary with a special End of the Year 10th Anniversary Fund-Raising Campaign. One of our over 1200 members has agreed to match your donations, dollar for dollar, up to a limit of \$5000. We “kicked off” this effort with an internet splash for #GivingTuesday, and we will continue until the end of 2017.

So let's make it happen! Help us help to Educate and Support Bay Area kidney patients. There are two ways to donate:

- Use your credit card online at www.baakp.org and click DONATE at the top
- Mail a check to **BAAKP > PO Box 2332 > Menlo Park, CA 94026**

Thank you, everyone, for your support over the last ten years. Let's make it another decade! Kidney Patients Rock!



Why Do I Need This Handful of Pills? With Dr. Shubha Ananthakrishnan

Shubha Ananthakrishnan, M.D., Nephrologist, Associate Clinical Professor of Medicine, from UC Davis answered this complex question on May 21, 2017, at the Palo Alto Medical Foundation.

The stats of “Pill Burden”:

- Among adults over the age of 65, about half take 5 or more medications
- About 12% take 10 or more medications



Many patients are provided numerous pills throughout their lifetime. How did they get there? Multiple doctors that treat various medical challenges prescribe what they feel is necessary for each diagnosis. It's no wonder that patients struggle in a web of confusion. Often it appears as if “one person doesn't know what the other person is doing.” As we know, most cases of Kidney Disease involve multiple diagnoses. Therefore, numerous medications are given to treat

chronic conditions such as diabetes, hypertension, kidney disease and transplant. Visits to one doctor

lead to one pill, another doctor, and another pill. The number of medications tends to create “tremendous room for error” and drug interactions. Some medicines seem to do more harm than good.

In this day and age, medications have contributed to many advancements in our health and well-being.

There are “methods to the madness.” Benefits include:

- Make us live longer
- Feel better (e.g. toothache, back pain)
- Make an impact on an organ from getting worse (chronic disease states).

Taking pills and getting results takes time. Some affect other organs; the impact is often unknown for years. Living in a society of “instant gratification” complicates things; we want results “quickly,” and it's

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Why Do I Need This Handful of Pills? (continued from page 4)

not that simple. As a result, patients often have a hard time accepting medications for chronic conditions. Patients need to understand the purpose and long-term effects of the medication.

Patients with kidney disease are affected in many ways. Medications are used for chronic kidney disease (CKD), before dialysis. Then, medications (such as binders) are used for dialysis patients. Ultimately, when a dialysis patient has a transplant, they are given more medications. It all adds up! Over time, these patients encounter a large “pill burden.”

The most commonly used medication classes for Kidney Patients are:

- Blood pressure (BP) lowering medications
- Diabetes medications
- Cholesterol medications, “statins”
- “Binders”
- Vitamin D agents

Many Hypertensive patients *without* kidney disease use blood pressure lowering medications, which enable patients to live longer and beneficially impact other organs. For patients *with* kidney disease? **For every 5 points reduction in blood pressure, cardiovascular events are reduced by a sixth!** (Medication choice didn’t seem to matter). Sometimes it takes 2-3 different pills to reduce blood pressure.

If the BP medication is not working, the patient needs to reduce their salt intake. Blood pressure CAN be reduced with the correct BP meds and a low salt diet. Please allow the medications time to work. Another benefit of a lower salt diet is the reduction of “proteinuria” (the amount of protein in one’s urine).

Proteinuria is one of the indicators of kidney disease.

Dr. Shubha then moved on to the subject of “the magic kidney pills.” These are blood pressure pills. ACE inhibitors are the “prils” (example: LisinoPRIL), and ARBs are the “Tans” (example: ZarTAN). If you have kidney disease, ask your doctor, “Do I have protein in my urine?” With sodium restriction, the “prils” and “tans” are beneficial! They **slow down the progression** of kidney disease and work best when sodium is restricted! Many patients are not willing to take the “prils” and the “tans” because they dangerously increase potassium levels. Doctors know that BP lowering medications can lower the risk of heart events. Dialysis patients with BP issues need to seek out strategies to reduce pill burden.

High BP in dialysis patients can be related to increased fluid gains or changes in “dry weight.” If a patient’s “dry weight” is incorrect, this can affect blood pressure. Another means of BP control would include more frequent dialysis or nocturnal dialysis, which have resulted in excellent BP control with fewer medications. BP lowering medications have beneficial effects on other organs, such as reducing strokes and heart attacks. Follow these tips to protect your kidney!

Regarding the “statins,” the benefits seem to differ based on pre-dialysis versus on-dialysis. In general, if you are over the age of 50 and have kidney disease, statins seem to reduce the risk for heart attacks and strokes. Large trials show no benefit of statin drugs in patients already on dialysis!

Dr. Shubha then addressed the medications known as

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

Board of Directors

Christie Chapman
Debra Elmore
Karen Soo Hoo
Matt Reeder
Linda Umbach
Walt Umbach
Phil Wyche...

And to countless Speakers,
Sponsors, and Volunteers

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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.

Why Do I Need This Handful of Pills? (continued from page 5)

“binders.” They are one of the most common medications used in patients with kidney disease. Because patients have to take so many binders, it adds to the pill burden as well as increases costs.

“Binders” bind **phosphorus**. Our bodies need phosphorus, but excess amounts can be a problem. Kidney disease is the most common cause of excess phosphorus accumulation. High levels of phosphorus cause damage to blood vessels, heart valves, and other tissues. It also creates bone problems. Because the effects of excess phosphorus on the body, taking binders are important to the health of dialysis patients.

Observational studies show being on a phosphate binder reduces the risk of dying. Using binders reduced damage to the blood vessels and the risk for painful skin lesions called calciphylaxis. Importantly, when phosphorus levels are controlled, so is itching! Talk to your dietitian about phosphorus control. Suggested ways to reduce pill burden from phosphorus binders:

- Talk to the renal dietitian.
- Identify sources of hidden phosphorus in foods.
- Talk to the nephrologist about alternate dialysis modalities. (More frequent dialysis is associated with better phosphorus control on fewer medications!)

During her residency in Canada, Dr. Shubha witnessed nocturnal dialysis patients who do not use binders and often needed supplemental phosphorus because their levels were so low. They were able to eat a normal diet, even foods that were deemed “phosphorus rich.”

Vitamin D compounds are used to control hyperparathyroidism. The parathyroid glands are located in your neck. When your parathyroid

hormone (PTH) levels are too high, the excess PTH “chews on the bone” by depleting calcium, which can affect the health & structure of the bone mass. Vitamin D and binders offer bone protection and other benefits to blood vessels, heart, and vital tissues.

Briefly addressing transplant medications, she noted they are absolutely needed to prevent the organ from being rejected! Side effects can be managed, for example, by converting from one medication class to another. However, one of the largest problems remains — **adherence to transplant medications**.

“Compliance” is especially challenging, particularly in young adults, who remain vulnerable as they are unfamiliar with having a “pill burden” and managing multiple medications.

Dr. Shubha noted the absolute need for caution when taking “handfuls of medications.” So, be careful! There is always the potential for drug interactions (how one medication might affect another). The possibility of error is high; costs can escalate. There are problems with additive side effects. Medications most likely to be implicated are blood thinners and diabetic medications. When taking multiple medications, be sure to ALWAYS keep an updated list – a list written down in your wallet or purse, or on your cellphone (take a photo of each pill bottle when visiting the doctor). Smartphone apps such as “**ListMeds – Free**” are easy ways to help keep an updated list of medications handy at all times.

She concluded her presentation by stating that medications can create a large “pill burden,” and patients must remain vigilant about reducing the potential for error. Remember — medications are beneficial, can have side affects, and should always be taken as the doctor prescribes.

From a Small Hope to a Large Miracle

My name is Robert C. Neal, a recent kidney transplant recipient. My kidney failure was induced by drug abuse, hypertension and diabetes. When my wife passed away unexpectedly, it took me into a



downward spiral since she always encouraged me to change my bad habits. My life depended on it. Little did I know my health was about to change in a dramatic way.

In 1990 I was diagnosed with hypertension and diabetes. I was treated for both the high blood pressure (hypertension) and diabetes; however, my doctor failed

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to mention the possibility of kidney failure if I didn't control my blood pressure, lose some weight, and diet better. I never paid too much attention to my diet and weight gain because I was always a hefty child. I became a Chef (which didn't help because I enjoyed eating). I started working on losing weight and controlling my blood pressure at the advice of family.

In 2013 my energy level was starting to decline, and I required rest often. Never did I realize my kidneys were on the decline. After a routine doctor's visit and blood work, I was informed of some news that had me worried beyond belief. The blood test indicated my creatinine level was slightly rising. I was placed on additional medication to keep my blood pressure down and to stabilize my creatinine. Things started to change swiftly for me, and I was not prepared.

On a riding trip to Las Vegas with my motorcycle club, I began feeling a little strange, not sure if it was due to the ride and the heat. I had become lethargic and fatigued. After resting I felt better. The next day, on the way back to the Bay Area, fellow bike members noticed that I was riding erratically, so I rode home in a car with friends. Later that evening when I awoke, my son noticed I was responding incoherently, so he called 911. When the paramedics arrived, they checked my blood sugar. It was 38, so I went to the ER. After I was stabilized and tests run, I was told it was possibly kidney failure. This was the first time I realized how serious my condition was. I was afraid because I wanted to live.

Shortly after the Las Vegas incident, and not feeling too comfortable with my current physician, a friend suggested I find a Nephrologist. I joined the Palo Alto Medical foundation Nephrology department under the care of Dr. Gottheiner. He began to educate me on preventative measures to avoid dialysis.

In 2014 my creatinine level rose above 7. I had a fistula inserted for dialysis. Several weeks later, I started in-center hemodialysis. The possibility of *not* doing dialysis was no longer an option. It was something I had to adjust to – because I *had* to do it. Meanwhile, my doctor's office submitted my name to the UC Davis and California Pacific Medical transplant lists.

In 2016 while waiting for an appointment at PAMF, I noticed a BAAKP newsletter. I read an article about a kidney transplant patient I knew, Phillip Wyche. We were childhood friends since elementary school. I contacted Phil, who was a board member with the BAAKP, and he encouraged me to attend one of the support group sessions. After I attended several

support group sessions, it gave me a renewed hope and a reality check that a transplant was possible. The support group was very encouraging and positive.

At one of the BAAKP support group sessions, I met a transplant patient Iris Corina. She recommended I contact Vickie Martin a transplant team coordinator at California Pacific Medical Center. After the interview, I was qualified as a transplant candidate. Not promised, I was hopeful to hear something by year end 2016 (although my blood type waiting period was 6-8 yrs.). I was excited and optimistic about the possibility of receiving a transplant. I continued to be compliant with my dialysis, weight, and diet.

My mother (and my best friend) who is 84 told me a few days before Christmas 2016 not to be surprised if they called me on Christmas day. It never occurred to me she would be right. On Christmas morning, I received a call from California Pacific Medical Transplant Team that a kidney was available for me. I assured them I was ready; and they advised to enjoy my Christmas and report at 6:00 am December 27. I was overjoyed, nervous and scared.

I arrived at the CPMC at 5:30 a.m., no longer worried. I had just completed my last dialysis treatment when they took me to surgery for my new beginning. The implanted kidney “woke up” right away and was functioning as expected. However, during a routine examination on the 4th day, a hematoma was found. I was taken back to surgery to drain the hematoma. After the fifth day, they noticed I was not putting out a significant amount of urine. After examination it was determined that one of the tubes was not fully connected to the kidney, and urine was seeping into my abdomen. By this time, I was tired, fearful, and began to lose hope—wondering if this was all worth it. But I was reminded that “if God brought you to it, he would bring you through it.” In a matter of 14 days I had had three surgeries. I came home January 7, 2017 with a fully functional kidney.

It has been 10 months since my transplant, and I haven't felt this good in over thirty years. I am thankful for the love and support from my family and friends, CPMC transplant Team, Dr. Gottheiner, Dr. Hassoun, Dr. Garb, BAAKP, Iris Corina, and Vickie Martin. I couldn't have done it alone. I praise God for loving me despite my faults.



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Kidney Patients!***

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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!



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)

- Feb 11, 2018
- Apr 8, 2018

East Bay Events

Samuel Merritt Health Education Center,
400 Hawthorne Ave, Oakland, CA, 94609

Educational Presentation (1-4 pm)

- Jan 28, 2018

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

Support Group Meetings (1-3 pm)

- Jan 7, 2018
- Mar 11, 2018
- May 6, 2018

Board of Directors' Meetings

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

**Save the Date! January 28, 2018
Home Dialysis and Kidney Transplant**

On Sunday, January 28, 2018, at our 36th
Educational Presentation since our founding 10
years ago, BAAKP will feature two special speakers.

Graham Abra, MD, is Medical Director,
WellBound San Jose; Clinical Assistant Professor,
Stanford University and Director, Medical Clinical
Affairs; Satellite Healthcare. Dr. Abra will discuss
Home Dialysis: the advantages and techniques.

Also speaking will be **Nikole Neidlinger, MD**,
Kidney Transplant Surgeon, California Pacific Medical Center and
Chief Medical Officer, Donor Network West (the
local procurement organization for transplant
organs.) Dr. Neidlinger will reveal the world of
organ donation from the donor to the recipient.
Don't miss this event on **January 28, 2018**, from 1
to 4 pm, at the Samuel Merritt Health Education
Center, 400 Hawthorne Ave, Oakland, CA, 94609.

Reserve your seat now at <https://tinyurl.com/BAAKP-Jan2018>,

email us at info@baakp.org or call 650-323-2225.

This event is sponsored by:

