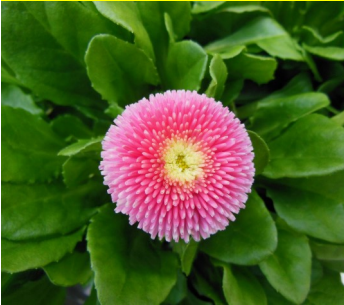


Volume 10, Issue 2

Spring 2017



Bay Area Association of  
Kidney Patients

Kidney Konnections

## Fancy meeting you here!

The Bay Area Association of Kidney Patients was surprised to learn that two of its members received kidneys in the same "transplant chain." There were 4 donors and 4 recipients in this elaborate kidney swap, which took place on May 27, 2016 at the California Pacific Medical Center. The surgeons transplanted kidneys from living donors into James Billbury and Alan Lapp. Both gentlemen were BAAKP members, but had never met one another. Follow their stories...

## Fighting Their Way Through the System to a Successful Transplant



Vallejo residents James and Emelda Billbury have learned much along the way to a transplant, and they wish to share it with our readers.

In 2014, James (a VA patient) learned from an outside family doctor that he was suffering from kidney disease. Then, returning to the VA, they told him he had a GFR of 30 and could see a dietitian in 3 weeks. Three weeks? Three weeks later, his GFR was down to 19, and they didn't know what to do! They were alarmed. Desperate, he found BAAKP and called our number (650-323-2225). Advised to get Risa Simons's book, *"Shift Your Fate: Life-Changing Wisdom For Proactive Kidney Patients,"* they were invited to come to the next meeting. James and Emelda became regulars at the BAAKP Educational presentations and Support

Groups.

They had a fortuitous encounter at one of the Support Group meetings with Faith Tootell, a well-known renal dietitian, who took James under her wing. She immediately referred them to a dietitian at WellBound in Vallejo; "Go now," she said. James liked the proactivity of the BAAKP group vs. the passivity of the people at VA. He was advised to get his "numbers" (laboratory results) and bring them to the next BAAKP meeting.

Meanwhile, his VA nephrologist had offered James hemodialysis at VA Martinez, nothing else. This nephrologist gave James & Emelda the impression that they were "bothersome," and the doctor seemed "dismissive."

James asked for a referral to Travis AFB. Still feeling lousy, but hopeful, he began to advocate for BAAKP and himself. James was constantly contacting the higher ups in the VA system -- through the VA MyHealth website emails and phone call after phone call.

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

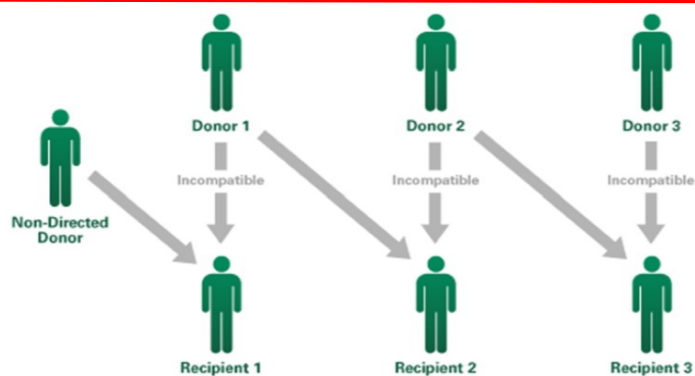
## Successful Transplant (continued from page 1)

At a BAAKP Educational Presentation, James met the local NxStage home hemodialysis representative. From him, James learned that NxStage was not available through the VA at Travis Air Force Base. At that time, James learned that veterans who are eligible for VA care are also eligible for Department of Defense care (which has more funding) if you live near a military facility. When he was transferred to a new nephrologist at Travis AFB in Fairfield, he found a nephrologist there who was eager to help. James still wanted NxStage, which Travis VA did not offer. His new Nephrologist at Travis, working together with the social worker there, referred him to the VA in San Francisco.

Meanwhile, anxious to get a transplant through the VA, James went through the many tests which were to be submitted to the VA transplant center in Portland. Portland kept waiting for the “package” from the VA in Martinez. It didn’t happen because, as James learned, they did not have a transplant coordinator at that VA. After James complained, the package suddenly appeared in Portland!

Finally, the nephrology department at San Francisco VA contacted him. James forwarded the information about the VA transplant and WellBound, and the head Nephrologist directed that James be moved to “private sector” because the services James was requesting (NxStage) were not offered by the VA. (By law, James had to get the best treatment available, and the VA authorized his treatment with WellBound, and the VA would pay.) James finally succeeded in getting the NxStage home hemodialysis he wanted; dialyzing five nights a week enabled him to feel so much better.

Because he was now under “civilian care,” he was now eligible for a transplant at a non-VA hospital. The tests were all done at the VA, and California Pacific Medical Center (CPMC) Kidney Transplant Team accepted those VA tests. His interview at CPMC was in April 2016; and within the same month, he received a call from CPMC that he was scheduled for surgery in May 2016. Astounding! James and Emelda were in shock. One month! They were to be part of a transplant chain, where incompatible donors and



Transplant Chain Diagram

recipients are matched. (An altruistic donor’s kidney is transplanted into a matched recipient who had a donor willing to give a kidney that was not a match and so on.)

They learned that their 24-year old daughter Regina, who was a different blood type, was to be the donor. After much discussion and concern for their daughter, they decided to go ahead. The transplant chain consisted of four living donors and four recipients. One recipient was Alan Lapp (see accompanying article). James and Alan met before surgery, not knowing that both were members of the BAAKP. It wasn’t until later, both realized they were part of the same kidney-support organization.



James was back at work in one month, manning the phones in the office; it was four months before he tackled the physical part of the job.

James credits his wife Emelda for helping him every step of the way, for being his right-hand and helping with the home hemodialysis.

James also wants to thank the BAAKP volunteers for doing the great work to get information to patients who would not have it otherwise. Without it, James feels he would still be on in-center hemodialysis in Martinez and in bad shape. BAAKP cannot do the work for you; but as James and Emelda did, you can be proactive too, and “fight your way” through the system!

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

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## He Knew His Kidneys Would Fail, But Not When...

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East Bay resident Alan Lapp lost his father to Polycystic Kidney Disease (PKD); his Dad had been on dialysis for 13 years. His older brother eventually developed PKD as well and also went onto dialysis, passing away in 2009. Neither his father or his brother pursued a transplant due to cardiac health issues.

Al was officially diagnosed with PKD in 2009. Al also had Atrial Fibrillation (Afib, the most common abnormal heart rhythm) and knew, to receive a transplant, his heart condition needed to be treated. After his diagnosis of PKD, he endured 3 surgical ablations (procedure where doctors destroy tiny areas in the heart that are not working properly) for his Afib, the third being successful. Al's wife Zina Derestky was aware that they must aggressively pursue a kidney transplant. Zina undertook to spread the word via social media, starting a blog, and spending a lot of time with one-on-one communications with doctors, donor advocates, and potential donors. Each potential donor had a maze of paperwork and multiple labs which needed to be coordinated. Zina even spearheaded a lapel pin project. At one point, nearly every one of Zina's FaceBook friends had the lapel pin as their temporary avatar. Al and Zina went to support groups such as BAAKP and the PKD Foundation. Al described the doctor visits and the blood draws as his part time job.

In 2013, when Al hit a GFR of just under 20, his nephrologist Dr. Ole Dierks advised them to seek a transplant. They investigated multiple transplant centers: Northwestern, UC Davis, UCSF, CPMC. (You can be on more than one kidney transplant list; they must be in different Organ Procurement Organization, or OPO, regions.)

Al had an amazing 36 potential living donors! (One of those potential donors, while being screened for donation, received an extremely early, life-saving diagnosis of prostate cancer.) Northwestern in Illinois has a unique program that requires a very closely matched donor, involves stem cell injections, and then the possibility of eventually not needing anti-rejection medication. Unfortunately, Al had an adverse reaction to the cells of the potential donor, which took the transplant he was scheduled for off the calendar.

Al and Zina maintained their vigilance, exploring other possibilities. Al was listed at California Pacific Medical Center (CPMC) in San Francisco. One



of his many potential donors, their Berkeley friend, Jen would be his donor. (Al's wife Zina was not a candidate, as she had one kidney that was too small.) A key factor that attracted them to CPMC was that they were willing to remove Al's enlarged PKD kidneys during the transplant surgery. The PKD



kidneys were uncomfortable; it was difficult to move, and their size affected his blood pressure when bending.

They were notified in April 2016 that CPMC had put together a "chain" involving four donors and four recipients. (A chain involves the donation of a kidney from an altruistic donor to anyone using a computer program MatchGrid to match others. The first recipient's live donor then donates to another and so on.) The chain appealed to Al's donor Jen because she felt more comfortable giving to one of a group than to Al directly, which eased the pressure of giving the organ to her friend and hoping the kidney responded well. Also, the recipients will probably get a better "match" of various factors such as antigens or the physical size of the donor's kidney, than with direct donation.

The chain transplant was scheduled for May 27, 2016. At that point, Al had been on dialysis for nine months; three months on in-center hemo and then six months on home PD.

Problems developed immediately after surgery. Doctors discovered quickly that his creatinine levels were up to 38! That high reading was due to leakage in one of the ureters, which connect the kidney to the bladder. He received emergency dialysis and was returned to surgery. He was in operating room for six hours for transplant and then another five hours for the leak correction. He also had a mild rejection episode in the hospital (not uncommon) which was treated with steroids; in total, he was in the hospital for 10 days, not the usual 3 to 5. Zina used Twitter to let their vast network of friends and family know of Al's hospital progress.

Their friends had a pool going about the size of the kidneys. Al thought they were huge and they did interfere with his ability to bend and to use a belt. They turned out to be 6.6 pounds, not the 20-30 pounds he expected.

It is now 10 months post surgery. His mental fuzziness has almost completely disappeared, but he finds the physical exercise he's wanted to do for years has been difficult. Dirt-biking and snow-boarding leave him sore and exhausted. Al

(Continued on page 4)



says, “In retrospect, I would have worked harder at staying fit before surgery, instead of being so sedentary.”

Al and Zina consider both the kidney gift and the transplant

as miracles. They state that the whole process is an exercise in problem-solving. And, when you are positive, you can work out the problems; when you are negative, the solutions are harder to find.

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## UCSF Kidney Transplant

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Shiang-Cheng Kung MD, Transplant Nephrologist and Clinical Professor of Medicine from University of California San Francisco, volunteered his time to speak at our January 29, 2017 Educational Presentation.

Dr. Kung reported that UCSF has approximately 5000 patients on the kidney transplant waiting list, and adds about 800 patients per year, transplanting about 350 per year. UCSF has performed the highest number of kidney transplants annually in the United States for the past four years. (Also note that UC Davis transplant center has a similarly high annual transplant volume.) Recently, the UCSF transplant program experienced a living donor death, which invoked their staff to take a “deep dive” into their procedures to determine if this could have been prevented. After this investigation, their procedures have been tightened, and UCSF now endeavors to gear up to normal transplant volume to safely and confidently serve as many recipients as possible.

The two most common causes of kidney disease are Type 2 Diabetes and high blood pressure, followed by a wide range of other diseases or conditions.

**For the most ideal health and lifestyle outcome, one should strive for a pre-emptive transplant before dialysis is needed.** To be eligible for a transplant, one needs to get on the transplant waiting list; and **to be on the list, you do not need to be on dialysis.** For this reason, Dr Kung encourages his patients to be evaluated for transplant once their 24-hour urine creatinine clearance--or the **eGFR--is less than 20 milliliters per minute.** In any case, **once dialysis begins, you are eligible to be on the transplant waiting list.** There are 3 main conditions that will likely exclude you from the waiting list once you are medically evaluated: cancers, infections, or heart/lung disease. Please note that HIV-infection generally does NOT exclude you from the transplant

waiting list. Lastly, understand that having good social support and caretakers will be crucial, especially in the few weeks after transplant, so the transplant evaluation team will also look at this factor.

**Transplant evaluation** includes a short introductory overview of the process, followed by tests which include blood tests as well as others to assess a potential transplant recipient’s health status and ability to undergo the transplant surgery. As part of the evaluation, you may need to visit other physicians and health professionals. Some patients might be placed on the list quite quickly; other patients’ cases might be evaluated longer, or they might need to take further medical tests. The goal of these tests and physician visits is to make sure transplant surgery can be performed safely without foreseeable complications.



**Once you are listed, you begin to accumulate time on the waiting list.** You are categorized on the waiting list by your blood group type (in order of increasing waiting time by blood type): AB, A, O, and B (type AB has the shortest wait time, type B the longest). Every recipient is ranked by the number of days waiting in their respective blood group; whenever an organ is available, the person with the longest waiting time is the next in line to receive the organ. The United Network for Organ Sharing (UNOS) is the official organization that divides the United States into 11 organ sharing regions, and California is in UNOS Region 5 with four other states

(Continued on page 5)



**Answering Questions: Dr. Kung; Sandy Del Grosso, BSN, RN, PHN, CNN, Kidney & Pancreas Transplant Coordinator; Crystal Rogers, RN, BSN, Living Donor Transplant Coordinator**

In Northern California there are two organ banks serving four transplant programs: UC San Francisco, UC Davis, California Pacific Medical Center and Stanford Hospital. The organ banks will first try to match the organ locally. If no match is made, then the organ is made available to the UNOS Region 5, then after that to a national match.

**“High-risk organs”:** Those organs from donors with potential of transmission of HIV, Hepatitis B, or Hepatitis C are classified with a label of “high-risk.” Despite the organ being given this label, you should still seriously consider accepting that kidney because it is likely to be a good organ, and may not actually carry this infection. The “truly high-risk” donated organ might be from a donor whose lifestyle would pose a genuine risk of those infections that might be due to pervasive illicit IV drug use, for example. You should discuss with the transplant team your right to turn down the organ based on the real-world possibility of the offered organ of actually transmitting those infections to you.

**How will you know if the organ you are offered is “good”?** The transplant center uses the Kidney Donor Profile Index (KDPI), created as a kidney ranking system. The criteria (such as donor’s age, BMI, ethnicity, health history) are calculated together to make a ranking for the organ. You will be first offered an organ with a standard ranking of 85% or lower, (the formal designation as a “standard” organ.) In some patients it may make sense to accept a kidney with a higher KDPI (86% to 100%); these kidneys, due to the donor’s health status, resulting in an increased chance that the organ may not last as long as the “standard” organ. At the time of listing, if your transplant team feels that you should consider receiving this group of organs *in addition* to the

“standard” organ, then you will be asked to sign a separate consent. Being on the **higher KDPI** (86% - 100%) wait list does not alter your position on the “standard” list or exclude you from being on the “standard” list.

**How will transplant affect my life?** You should probably plan on not working or traveling or any vacations for the first 3 to 6 months after transplant. You will need this time to recover and heal. Be prepared to be diligent about the post-transplant medications for the rest of your life. (If you are not ready for this, the transplant center needs to find a recipient who will responsibly care for their transplanted organ.) Additionally, you will need to work with your medical team to deal with any side effects of your medications.

**You have a lot to look forward to after your transplant.** Food will taste better and you will feel so much more energetic. Without dialysis, you’ll have more free time! After waiting for an average in Northern California of 7 years, you have a new life with your wonderful new kidney!

Thank you Dr. Kung, Ms. Del Grosso and Ms. Rogers for helping to Educate Bay Area Kidney Patients. Our speakers can be reached at UCSF Kidney Transplant (415) 353-1551 or

[www.ucsfhealth.org/clinics/kidney\\_transplant/](http://www.ucsfhealth.org/clinics/kidney_transplant/)



## Angel Flight West



**Mr. Robert Strawn, of Angel Flight West spoke about his non-profit organization that is ready to help patients and families. If you know a pilot, you know that they have great joy in flying. Angel Flight's pilots love to share that joy, especially in service**

**to those in need.** ANGEL FLIGHT is a U.S. nationwide organization of volunteer private pilots who donate their valuable expertise, flight equipment, and professional time to help those in need. Their primary target service audiences are those who are transportation-disadvantaged in need of help to reach non-emergency medical treatment, or disease management; and also help victims of violence achieve safe relocation, among other needs. Alaska Airlines also donates significant resources toward these missions. You can volunteer to help Angel Flight in their mission of hope by:

- becoming an "Earth Angel," their service that provides last-mile ground transportation in flight destination locales (click [angelflightwest.org/earth-angels/](http://angelflightwest.org/earth-angels/))
- donating your Alaska Airlines flight miles (contact [alaskaair.com](http://alaskaair.com))
- becoming a Mission Assistant, flying "shotgun" on a mission
- if licensed, becoming an Angel Flight pilot or safety committee-member
- helping office/dispatch staff, marketing and outreach -- in-office or remotely
- donating money for support



ANGEL FLIGHT WEST (AFW) is the western-most region administering help to folks in 13 western states. Their Northern California pilots routinely provide service to UCSF, Stanford Children's Hospital, and

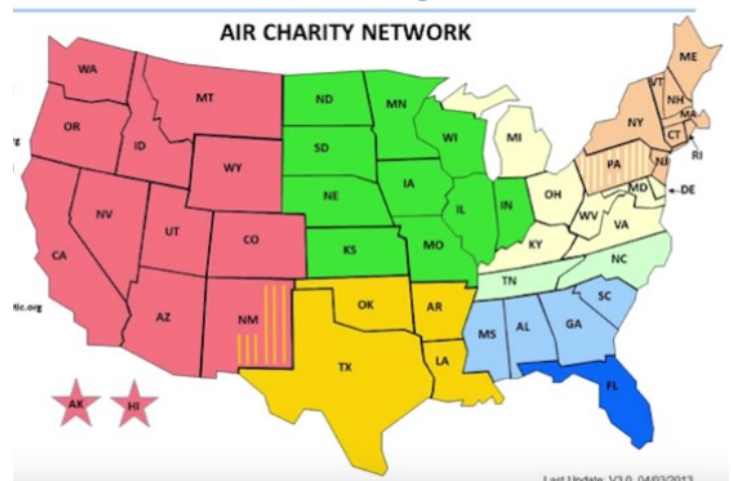
Stanford Medical Center; flying regularly in and out of Palo Alto and Oakland airports among others; serving areas in California from Crescent City to San Diego.

Angel Flight West Facts and Figures	
Year Founded	1983
# Volunteers	1,900
# Volunteer Pilots	1,000
Value donated	\$40,000,000 and counting
Cost to patients	\$0.00

Angel Flight analyzes the disease conditions and geography of need to ensure their service readiness. They have found there are some areas of higher incidence of some conditions coupled with fewer medical resources in that area -- thus they can focus their resources. But this is not the only kind of medical need they provide. You can:

- fly in your family-member to your location to provide caretaking after a surgery
- fly once a week to a distant city indefinitely if necessary to receive experimental care at a distant clinical research facility
- fly to a distant specialty medical facility to receive regularly-scheduled treatments indefinitely if necessary

### Where We Fly



(Continued on page 7)



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## Angel Flight (continued from page 6)

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Angel Flight's service area covers the lower 48 United States, Alaska, and Hawaii.

Angel Flight Divisions
Angel Flight West <a href="http://www.angelflightwest.org">www.angelflightwest.org</a>
Angel Flight Central <a href="http://www.angelflightcentral.org">www.angelflightcentral.org</a>
Angel Flight South Central <a href="http://www.angelflightsouthcentral.org">www.angelflightsouthcentral.org</a>
Angel Flight Northeast <a href="http://www.angelflightne.org">www.angelflightne.org</a>
Angel Flight Mid-Atlantic <a href="http://www.angelflightmidatlantic.org">www.angelflightmidatlantic.org</a>
Airlift Hope <a href="http://www.airlifthope.org">www.airlifthope.org</a>
Mercy Flight Southeast <a href="http://www.mercyflightse.org">www.mercyflightse.org</a>
Angel Flight Southeast <a href="http://www.angelflightse.org">www.angelflightse.org</a>

Kidney patients should be aware of some limitations of the service: Often, reaching your transplant surgery is urgent, so AFW generally cannot schedule a flight with less than 6 hours of notice. All patients served must be ambulatory, able to walk, sit up and move reasonably. Furthermore, most available airplanes are smaller aircraft with weight/space limitations, and some may be unpressurized.

To begin the flight request process, simply click on <https://afids.angelflightwest.org/flight-request> and provide the earliest notice possible. Or call **888-4-AN-ANGEL (888-426-2643)** Thank you Mr. Strawn for all you and AFW do to help patients and families.



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## Save the Date!



The American Association of Kidney Patients  
is pleased to announce the date and location of its  
2017 National Patient Meeting!

**September 8 – 10, 2017**

[The Vinoy Renaissance](#), St. Petersburg, Florida

Click [here](#) to reserve your room at a special rate for AAKP members

**Convention registration will open in March at <http://www.aakp.org>**

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***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!



***SAVE THESE DATES !***

***Peninsula Events***

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

***Educational Presentation (1-4 pm)***

- **May 21, 2017**

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

- **May 7, 2017**
- **July 9, 2017**
- **Oct 15, 2017**

***East Bay Events***

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

***Educational Presentation (1-4 pm)***

- **Sep 17, 2017**

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

- **Jun 11, 2017**
- **Aug 13, 2017**
- **Nov 15, 2017**

***Board of Directors' Meetings***

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

***BAAKP 10<sup>th</sup> Anniversary Party-May 21, 2017***  
***Artificial Kidneys & Kidney Medications***

Two special speakers are helping the Bay Area Association of Kidney Patients celebrate our 10th Anniversary year!



**Shuvo Roy, PhD**, bioengineer, and professor at the University of California, San Francisco (UCSF) of California San Francisco will join us on May 21, 2017, to present an update on the **implantable bio-artificial kidney**, hopefully another option for kidney replacement therapy. Also joining us will

be **Shubha Ananthakrishnan, MD**, a Nephrologist with UC Davis, with **"Help! Why do I need this handful of pills?"**



Join us on Sunday, May 21, 2017, from 1-4 pm for this **FREE** event. It will be held at the Palo Alto Medical Foundation, 3rd floor, Hearst Conference Center, 795 El Camino Real, Palo Alto, CA 94301. Enjoy 10<sup>th</sup> Anniversary Cake and special door prizes!

Reserve your seat: <https://tinyurl.com/BAAKP-May2017>

Or at [www.baakp.org](http://www.baakp.org) and click on the "Calendar" tab  
or call 650-323-2225.

Sponsored by

