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Spring 2016

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Bay Area Association of
Kidney Patients

Kidney Konnections

Kidney Transplant Today - The Stanford Program

We were most fortunate to have two doctors from the **Stanford Health Care Kidney and Kidney/Pancreas Transplant Program** join us on January 31, 2016. **Dr. Amy Gallo, Transplant Surgeon and Assistant Professor of**



Surgery and Dr. Colin Lenihan, Transplant Nephrologist and Clinical Assistant Professor spoke on "Kidney Transplant Today!"

Dr. Lenihan stated there were only 17,000 kidney transplants performed in 2014. Sadly, there are over 100,000 waiting for a deceased donor transplant. A huge imbalance!

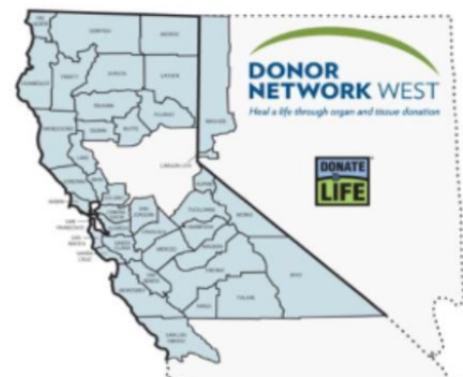
You can be listed for a deceased donor kidney transplant when your GFR is 20mls/min or less. GFR (Glomerular Filtration Rate) is calculated from blood tests: serum creatinine in particular. A GFR of 20 ml/min approximates 20% of kidney function, the normal being over 90. It is best to list when your GFR is 20 as you can accumulate waiting time while your own kidneys are still working. If you are already on dialysis at the time of your transplant evaluation, your waiting time is calculated looking back from your dialysis initiation date.

The transplanted kidney has a finite lifespan, and you do not want to "waste



your own residual kidney function" by getting a transplant too soon. Dr. Lenihan cautioned that in patients who do not yet require dialysis kidney transplant should be delayed until the patient is close to needing dialysis. .

Next he discussed the deceased donor kidney allocation system. There are 58 Donation Service Areas (DSA) in the US, with waiting times varying greatly. The DSA for Northern California is called Donor Network West and covers the areas in blue.



Most kidneys (70-80%) that are donated within a given DSA go locally to patients on the waiting list in that same DSA. Demand for kidneys varies widely over the U.S., significantly affecting waiting times. You can list at multiple kidney transplant centers in a different DSA but at additional effort and costs. Being multiply listed may increase your chances of getting a transplant more quickly.

The deceased donor kidney allocation system changed in December 2014. Under the new system the top 20% of deceased donor kidneys are matched with the 20% of candidates who are expected to need them longest. High antibody levels (sensitization) to

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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 interactive social website at www.baakp.org

Kidney Transplant Today (continued from page 1)

potential donors impede kidney transplants, making it difficult to find a matching kidney. The new allocation rules are intended to improve the chances of highly sensitized patients getting a transplant by giving them 1) extra waiting time points and 2) prioritizing them for organ sharing across the country.

Dr. Lenihan covered Stanford's selection of Transplant Candidates:

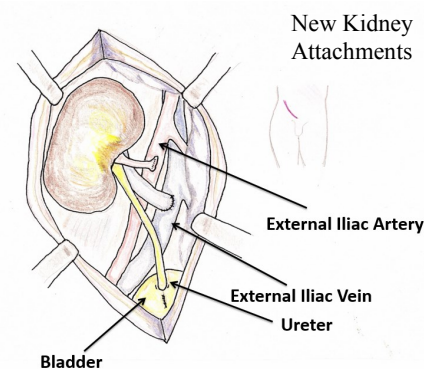
- No age limit
- Weight limit: usually won't transplant at greater than 35 BMI, can be listed at 40 BMI (Body mass index {BMI} is a measure of body fat based on height and weight that applies to adult men and women.) (See <http://www.cdc.gov/healthyweight/assessing/bmi/>)
- Patients may also be excluded because of:
 - active infection or cancer
 - severe heart or vascular disease that is not amenable to treatment
 - marked frailty or deconditioning

At Stanford, each candidate is evaluated for kidney transplant by a team that includes a nurse, physician, and social worker. The final decision regarding a patient's candidacy is made at a multidisciplinary 'transplant evaluation meeting'. If you're lucky enough to have a living donor, both recipient and the donor must have compatible blood types and tissue types. If the recipient and donor are incompatible, then a transplant can still occur with a paired donor exchange or desensitization therapy. (See <http://nyti.ms/1QMNg7T> for more about desensitization.) Receiving a kidney from a living donor is best because it has been shown that half of all living kidney transplants are still working after 12 years, whereas with a deceased donor transplant after 9 years 50% are still working.

After you receive the transplant, you will need to see the doctors at the transplant clinic twice a week; then in the second month, every week; in months 3 & 4, every second week; and in months 5 through 12, monthly, with care usually shared between your transplant and general nephrologist. After one year, follow-up is usually every 2 to 3 months. You will need to take 2-3 pills, such as Prograf, CellCept and Steroids for immunosuppression; 3 or so drugs to ward off infections (during the first 3-12 months), and the other usual drugs you take, such as diabetic medications or blood pressure medications. Signs of transplant rejection may be subtle. It is often

identified by a rise in your creatinine levels, so frequent blood tests are critical in the first year. With severe rejection, you may have pain in the area of the transplant, fever, and reduced urine output.

Dr. Amy Gallo then addressed the audience about the surgical aspects of a kidney transplant. She wants us to avoid the fear of the unknown by being fully informed. The surgeons take the calls from the Donor Network, which give them information about the donor and the recipient that has been selected. If the doctors at Stanford agree, then the coordinator calls the patient to see if they are ready and able for the transplant. After entering the hospital through "Admitting", they will do lab work, do an EKG, and other tests. While you are waiting, the surgeons examine the kidney to be sure it is good. Through your IV, they put you to sleep first, then place the breathing tube. Next is a central line (a big IV) in your neck, which stays in place throughout the entire hospitalization, allowing needle-free blood tests. You will start to receive anti-rejection medication; then they put an arterial line in your arm, enabling the doctors to monitor your blood pressure every second. A Foley catheter is inserted into your bladder to keep the bladder empty during surgery; this remains for three days, even when you are up and around. The bladder catheter makes it easier for surgeons to attach the new kidney ureter to the bladder during



surgery. Most of the time the new kidney is added to the right side of the abdomen because the anatomy on the right side is more favorable; the new kidney is attached to the vessels that run into your upper leg.

Meanwhile, while you are being prepped, the new kidney has been waiting on ice. The vein from the new kidney is attached first, then the artery. The new kidney "pinks up" and most of the time, the kidney starts making urine right away. Then the ureter is attached to the bladder. To prevent future kidney infections, Stanford takes an extra step when "closing up" by the tightening the muscle around the ureter. They use a double J stent in place, holding open the

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Kidney Transplant Today (continued from page 2)

urethra while healing. It is removed later.

Stanford tries to customize your medications; many patients may not need steroids. There are a few restrictions, such as stay away from martial arts & football, and wear a mask when you are around dirt (containing dangerous *Aspergillus* fungus) at construction sites.

Questions from the audience revealed more information.

-Dr. Gallo discussed living donor surgery, stating that family members are usually a good match. It's a long surgery because of the need for careful dissection of the donated kidney and its attachments. Donor surgery is done laparoscopically, as detailed in the other article for this publication.



Post-operatively, the donor may feel worse than the recipient because they have been feeling great before surgery, whereas the recipient feels poorly before surgery and afterward feels pretty good. Donation is associated with a small increase in the absolute lifetime risk of developing kidney failure when donors are compared to similarly healthy individuals who do not donate a kidney, however, the risk for donors is still lower than in the population as a whole. There is a small increase in the probability of developing blood pressure problems.

-Dr. Gallo clarified the incidence of infection. Nationwide the incidence of post-operative infection is 12-15%- Stanford achieves less than 10% post-operative infection.

-Removal of the patients' native kidneys is usually not done, except when the patients' kidneys are too large as in Polycystic Kidney Disease, and that is usually done in a separate surgery before transplant. The reason for this is because these large kidneys contain a large amount of blood, and removing them can cause the blood pressure to drop during transplant surgery.

-Dr. Lenihan discussed sensitization. Your blood is tested to see if you are sensitized by checking for the presence of antibodies against potential kidney donors. The test is referred to as the calculated panel reactive antibody (cPRA) and expressed as a percentage. A cPRA of 0% implies that a candidate will likely be compatible with most donors, conversely, a cPRA of 100% implies that a candidate will be incompatible with a sizable proportion of potential donors. cPRA is

discussed in <https://optn.transplant.hrsa.gov/resources/allocation-calculators/about-cpra/>. Stanford is unique in our area by doing desensitization for patients with high antibodies or ABO incompatibility.

-You can estimate your own EPTS (Expected Post Transplant Survival) score, which is used to select the donated kidney, by going online using your Date of Birth, whether you are diabetic or not, if you had kidney transplant or not, and the date you started dialysis. See

<https://optn.transplant.hrsa.gov/resources/allocation-calculators/epts-calculator/>

-Adrenal glands (which sit on top of the kidney) are not transplanted.

-When you have a Peritoneal Dialysis access, and if, during the transplant surgery, the kidney starts making urine immediately, Dr. Gallo will remove the peritoneal dialysis catheter and "put it in the trash can". The hemodialysis graft or fistula are usually not removed during transplantation or afterward.

-The oldest patient Dr. Gallo has transplanted is 70. (See *Kidney Connections* newsletter, Fall 2015 at baakp.org/newsletters detailing a transplant at age 78.)

-One of the problems with multiple transplants is the need for a good vascular access, and so each patient is evaluated individually.

Thank you Dr. Gallo and Dr. Lenihan of Stanford Kidney and Kidney/Pancreas Transplant for your wonderful presentation. You can be referred to Stanford by your Nephrologist, or you can self-refer by calling (650) 725-9891. Also a special thanks also goes to our event sponsor, Astellas Pharma US, and Wayne Klein.

Thanks to our many volunteers!

Past Board member, Ben Lee, was the Master of Ceremonies and did a masterful job! Virdie Reed was the photographer, Judie Sutton helped with the refreshments, and Colleen & Mark Boyce and Anna Mae and Rey Olivares were everywhere, helping wherever they were needed. BAAKP would not exist without our wonderful volunteers. Thank you all!

A video of this event will be available on our website, <http://www.baakp.org/video>.

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

Save the Date! National Convention!

The American Association of Kidney Patients, the national kidney-patient education, support and advocacy non-profit, has announced their **Annual Patient Meeting on September 23-25, 2016 in Nashville, Tennessee.**



For more info on the agenda in our Summer Issue or go to www.aakp.org or call **813-636-8100.**

Increasing Home Dialysis Use

Editor-in-Chief of Nephrology News & Issues, Mark E. Neumann, recently wrote an article about the huge difference between the number of dialysis patients who select “in-center” hemodialysis versus the few who use the various forms of dialysis at home.

Close to 90% of dialysis patients choose conventional treatment 3 times a week in dialysis centers. On the other hand, only about 10% of the patients choose home dialysis. Why is this? Before 1972, when the growth of for-profit dialysis centers began, about 40% of the U.S. patients were using home dialysis. By 1980, there were only 5% doing home dialysis.

Nephrologists themselves, when asked what type of dialysis they would do if they themselves had renal failure, chose peritoneal, short daily, or slow nocturnal hemodialysis—all home-based treatments. The U.S. lags far behind other countries such as Australia, Canada, Denmark, Finland, Iceland, Mexico, Netherlands, New Zealand, all have home dialysis rates at or above 20%.

Modern Healthcare Magazine in an October 11, 2014 issue said, “Research shows that patients on home hemodialysis or home peritoneal dialysis who dialyze 5 to 6 times a week have better health outcomes than those who visit an outpatient hemodialysis center 3 times a week.” Home based patients clean their blood more often.

Why does this disparity exist?

The Government Accountability Office (GAO) feels that the need to fill excess capacity in the overabundance of dialysis clinics, and create more profit for in-center treatments has resulted in a de-emphasis on home dialysis by dialysis providers.

Additionally, Nephrologists feel that they should receive the same payment for monthly care of both, the home or the in-center, dialysis patients. Moreover, the GAO asserts that the Medicare payment system favors in-center hemodialysis treatment over home-based treatments.

Federal Law dictates that all patients be educated about all dialysis modalities and that all treatments be available to these patients. The GAO asserts that the differences in the monthly “Medicare Capitated Payment” to physicians favors in-center dialysis, despite a similar investment of the physician’s time. Another factor is that the physicians may not be comfortable with the home-based procedures.

But, studies show that “when patients are presented home therapy options alongside the in-center dialysis option, they will select home therapy.” And new home based therapies are in the pipeline:

NxStage Medical and Fresenius Medical Care are working on new PD machines; Baxter Health Care has a new AMIA PD cycler; Baxter has a new home hemodialysis machine VIVIA in trials in the U.S.; NxStage Medical is working on a new version of SystemOne, the home hemodialysis machine; and Outset Medical will soon release a new compact home hemo machine Tablo.

Mr. Neumann encouraged all patients to take advantage of the Medicare Kidney Disease Education Benefit which provides up to 6 sessions of kidney disease education. All kidney patients should read all you can, ask questions and know the facts about all forms of dialysis.

Bay Area Association of Kidney Patients observed “Donor Sabbath”

On Donor Sabbath Weekend every year, we remember and thank all who have donated their life-giving organs. On November 15, 2015, BAAKP celebrated by joining with [Trinity Episcopal Church](#), Menlo Park, screening the award-winning film “[Perfect Strangers-the Movie](#)”. This documentary was produced by Jan Krawitz Documentary Filmmaker and Professor at Stanford University in the M.F.A. Program.

Over 100,000 persons are waiting, but only 17,000 kidney transplants occur each year. One way to increase the number of transplants is through kidney donation from living persons.

The Rev. Matthew Dutton-Gillett explained in his short introduction, that the Episcopal Church commends organ donation to its members as a response to the Christian call to love our neighbors and help those in need. He said, “There is no greater calling than to give of ourselves, and it would be hard to imagine a more generous act of self-giving than organ donation.” The 69-minute film documentary followed one remarkable woman as she embarked on an unpredictable, four-year donation journey; and another woman who endured daily home hemodialysis, waiting for the perfect kidney match.

A panel discussion followed the movie. We were



Left to right: Jan Krawitz, Thomas Kelly, Betsy Bucter

most fortunate to have Jan Krawitz, the producer, with us to share with us the stories of how the movie was created over a five-year period. Also joining us was Thomas Kelly, an altruistic (non-directed) living kidney donor, who discussed his donation surgery and his life today. Mr. Kelly is also a

member of Waitlist Zero, reviewed in an [earlier *Kidney Konnections*](#) newsletter.

Also joining the panel was Betsy Bucter, RN, MA, an Outreach Coordinator for the California Pacific Medical Center Kidney Transplant Program, who presented a thorough look at living kidney donation. The facts she presented were mind-blowing:

- 1 in 4 people will donate if they knew someone in need.
- There are 2 main types of living donation: directed (to someone special) and non-directed (altruistic).
- The advantages of a living kidney donation are: higher success rate, shorter wait, surgery can be planned in advance, and there is less incidence of kidney rejection after transplant.

She also dispelled common myths about living donation with these true facts:

- There is some pain after surgery; short-term pain medication alleviates this.
- Donors are up and around, out of bed and then sent home in 2-3 days.
- A donor should be able to return to regular activities and exercise in 6-8 weeks.
- A donor can enjoy normal meals and alcoholic beverages following donation.
- A donor can resume a normal sex life when feeling better and can become pregnant after 6 months.

To qualify as a living donor at CPMC, the candidate should complete an online questionnaire. Some hypertensive conditions, diabetes, heart disease, a recent cancer diagnosis, obesity, certain viral infections, psychological conditions and kidney problems may exclude a potential donor but always ask first. Next, a potential donor will take blood typing and cross-match tests. Most importantly, if one does not have the same blood type as the recipient, other programs exist, such as **Paired Donation and Donor Chains**. Your intended recipient will still receive a kidney under these unique ways to donate.

Ms. Bucter then described the surgery itself. Removal of the selected kidney is accomplished laparoscopically (without a large incision). There



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“Donor Sabbath” (continued from page 5)

will be three small incisions (about 1 cm or 0.39 inch) made at three key points in the abdominal area to enable insertion of instruments and a miniature camera. The camera is attached to a monitor that the surgeons view to guide their work. A slightly larger incision (about 8 cm or 3 inches) just above the pubic bone is used to remove the donor’s kidney.

Probably the most interesting fact that emerged from Ms. Bucter’s presentation was that the average person with two healthy kidneys has 8 to 10 times the kidney function than the body needs! Within six months after kidney donation, the remaining kidney

has fully adjusted to being the sole kidney. Kidney donors have the same life expectancy and lower rates of kidney disease than the general population. However, there is a small risk of high blood pressure. In conclusion, living donor transplants give the best chance of success and long kidney life for the recipients.

BAAKP Board member Matt Reeder demonstrated to the audience the effect of one living donor. One donor can be the basis for a “chain” of kidney transplants, enabling many who wait to get that kidney!

Demonstration of a “chain” that created a donor match for each recipient



Thank you, Rev. Matthew and *Trinity Church* for hosting this event and also to our panel members. Thanks go to Jan Krawitz for bringing “Perfect Strangers, the Movie”; which can be purchased at www.perfectstrangersmovie.com/buy. Also, we are happy that Thomas Kelly joined us; if you want more information on Waitlist Zero, go to <http://waitlistzero.org/>. We are also grateful to Betsy Bucter, from the California Pacific Medical Center Kidney Transplant Program; go to <http://www.cpmc.org/advanced/kidney/> or call 415-600-1700. Finally, we thank our sponsor, Sanofi (Genzyme). A video of this event will be available on our website, <http://www.baakp.org/video>.

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Are You Covered? by Matt Reeder

Are you covered? What does your insurance cover for your treatment? And for how long? If you are not covered, or need more coverage, maybe you need help. Our guest, Dedra Jize discussed some options: how to plan ahead for your coverage, how a caregiver or other advocate can help you get your benefits. One option available to many folks is coverage through Medicare for payment of your dialysis treatments.



You may enroll in Medicare Parts A (hospital), B (medical), and D (drugs) at any age if your kidneys fail and you need regular dialysis or have a kidney transplant and you have worked long enough to receive benefits under Social Security, or you are the spouse or dependent child of a person who has worked long enough to receive benefits under Social Security. (There are some other situations where you might be eligible for Medicare coverage.) If you are eligible, your Medicare coverage starts the first day after the 3rd full month of dialysis in a clinic. Medicare coverage can start sooner if you choose to do home/self-dialysis initially or switch to home/self-dialysis during the 3-month waiting period when dialyzing in clinic. For home/self dialysis, your Medicare benefits begin on the first month of dialysis if: You take part in a training program through a Medicare-certified training clinic; your physician certifies that you will finish home/self-dialysis training and do home dialysis or self-dialysis in a clinic. Medicare coverage also starts sooner if you have a kidney transplant. We strongly encourage our

members to explore home dialysis and transplant options as these treatments generally are better for you than in-center hemodialysis.

Medicare will not cover surgery for your dialysis access if the procedure is done before Medicare coverage starts for you.

If you have Medicare only because of ESRD, your Medicare coverage will end 12 months after you stop dialysis or 36 months after you have a kidney transplant and no longer need dialysis. Your Medicare coverage will continue if you restart dialysis or get a kidney transplant within 12 months after stopping dialysis. It will also continue if you start or resume dialysis or get another kidney transplant within 36 months after receiving a kidney transplant. Your Medicare coverage will resume without a waiting period if your ESRD Medicare ends after 36 months and you later restart dialysis or get another transplant.

Medicare Part B covers immunosuppressive drugs for 36 months following a successful transplant if Medicare Part A was in effect the month of your transplant and Medicare paid for the transplant. Some other situations may allow this coverage.

For low-income patients, Medi-Cal coverage can help you with Medicare payments. For more information, we recommend contacting California Health Advocates at cahealthadvocates.org or 1-800-434-0222 who can get you in touch with local volunteer Medicare counselors.

Thank you, Dedra, for your educational talk. If you would like more information, please contact Dedra Jize, OT, CSA, Geriatric Manager, Law Office of Roy W. Litherland, 3425 S. Bascom Avenue, Suite 240, Campbell, CA 95008, phone 408-356-9200, or email dedra@attorneyoffice.com.

Other Kidney Resources – Check www.baakp.org for more!

American Association of Kidney Patients AAKP

2701 N. Rocky Point Dr.
Suite 150
Tampa, Florida 33607
(800) 749-2257

www.aakp.org

San Francisco Polycystic Kidney Foundation

1-800-PKDCURE

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

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
www.trioweb.org

The National Kidney Foundation

131 Steuart St Ste 425
San Francisco, CA 94105
www.kidneyca.org
888-427-5653

www.kidney.org

Post Office Box 2332

Phone: (650) 323-2225

Email: info@baakp.org

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

Please visit our website at

www.baakp.org

to make a donation, see back issues 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 22, 2016**

Support Group Meetings (1-3 pm)

- **May 1, 2016**
- **July 10, 2016**

East Bay Events

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

Educational Presentation (1-4 pm)

- **September 18, 2016**

Support Group Meetings (1-3 pm)

- **April 10, 2016**
- **June 5, 2016**
- **September 11, 2016**

Board of Directors' Meetings

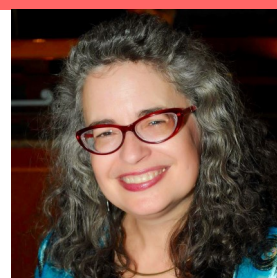
1st Tuesday of the month—6:00 pm

info@baakp.org (650) 323-2225

Coming on May 22, 2016

7 Ways to Know if You Are Getting GOOD Dialysis

On May 22, 2016, we will welcome a special guest speaker for the **Charles & Joan Homgren Kidney Education Series**, who is coming all the way from the East Coast. **Dori Schatell, MS**, is Executive Director of the Medical Education Institute, and Co-Author of “**Help, I Need Dialysis! How to have a good future with kidney disease**”. She will speak on the “**7 Ways to Know if You are Getting Good Dialysis**”. Joining Ms. Schatell will be the ever-popular patient panel of kidney patients, all sharing their experiences with various forms of dialysis.



Scan to register

Please join us on Sunday, May 22, 2016, from 1- 4 pm for this **FREE** event to be held at Palo Alto Medical Foundation, 795 El Camino Real, Palo Alto, CA 94301. Reserve your seat online at tinyurl.com/baakp-May2016 or www.baakp.org/events or call 650-323-2225 or scan the QR code to register. Refreshments and special door prizes too! Reserve your seat now!