

Volume 12 , Issue 3

Summer 2019

## Medicare Exposed!

Few issues are as complex as Medicare; this is especially true for kidney patients. In September 2018, we welcomed our speaker, **Mr. Marcelo Espiritu**, Director of the Sourcewise Health Insurance Counseling and Advocacy Program (HICAP). Sourcewise is the Area Agency on Aging in Santa Clara County. Medicare is a federal program for those over 65, under 65 with certain disabilities and any age with End-Stage Renal Disease (ESRD) and provides:



- Information to connect to resources throughout the county
- Care management for patients on Medi-Cal
- Senior employment for people over 55
- Meals on wheels (frozen meals)
- Health Insurance Counseling & Advocacy Program, a local source of help with Medicare

HICAP volunteer counselors trained and registered with the Department of Aging, help us to understand our Medicare options; they meet with clients in senior centers, health centers, and libraries. For counseling in Santa Clara County, call 408-350-3200, 1 for English, 2 for HICAP; in San Mateo County, call 650-627-9350; and 800-434-0222 for other counties.

The chart below details the parts of Medicare coverage. Original Medicare, Part A is for hospital/nursing home inpatient stays; Part B is for outpatient and physician services.

Medicare Benefits & Delivery		2. Managed Medicare "Medicare Advantage" (MA) Capitation
1. "Original Medicare" Fee-for-Service		
Part A	<input type="checkbox"/> Inpatient hospital care <input type="checkbox"/> Skilled nursing care <input type="checkbox"/> Home health care <input type="checkbox"/> Hospice care	<b>OR</b>  Must have enrolled in A and B  Cannot have ESRD... Unless with a company that also offers an MA Plan  Opens in 2021  20+ MA HMO Plans in Santa Clara County  <b>Part D Included</b>
Part B	<input type="checkbox"/> Outpatient care <input type="checkbox"/> Doctor's services <input type="checkbox"/> Annual Wellness Visit <input type="checkbox"/> Preventive services <input type="checkbox"/> Home health care <input type="checkbox"/> Diagnostic tests <input type="checkbox"/> Some therapies <input type="checkbox"/> Durable medical equipment	
Medigap	<input type="checkbox"/> Plans pay A/B out of pocket costs	
Part D	<input type="checkbox"/> Outpatient Rx drugs	

See page 3 for included and non-included charges.

(Continued on page 3)

Bay Area Association of  
Kidney Patients

*Kidney Konnections*

## 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)

# Kidney transplants without transplant pills!

Kidney Transplant Surgeon and Chief Medical Officer of **Medeor Therapeutics**, **D. Scott Batty, Jr., M.D.**, spoke at both our September 2018 and March 2019 Educational Presentations. Medeor Therapeutics sponsored both events, hoping to locate transplant candidates with a living related donor who may wish to donate a kidney.

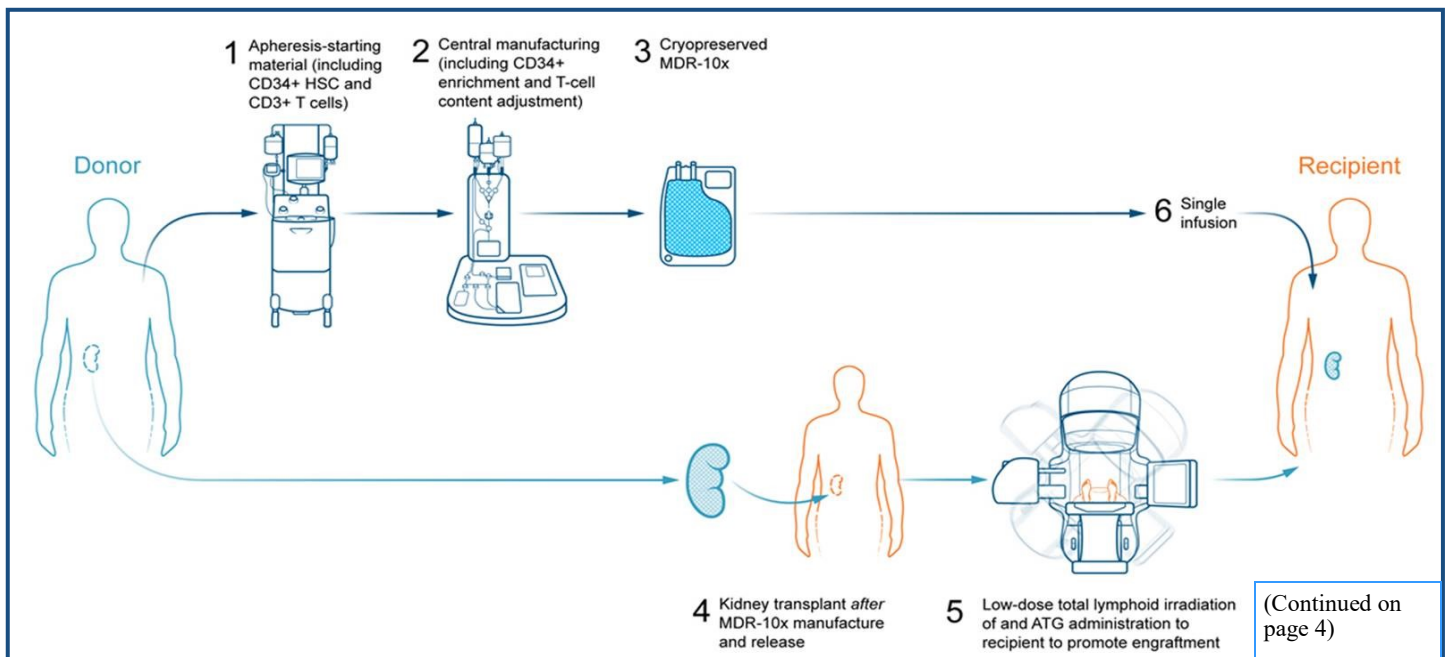
There are 94,754 people awaiting kidney transplant, with only 21,167 transplants taking place in 2018. Of those, there were 6,442 living donor transplants; the balance came from deceased donors.

When a person receives a transplant, there is a risk that their own immune system will recognize the donated organ as “foreign” and will attack or reject it. To help prevent this, high doses of anti-rejection medications are usually given for several months or years after surgery. Unfortunately, immunosuppressive therapies also involve significant expenses and potentially severe side effects such as infections, diabetes, cancer, and heart disease. The current “state of the art” for immunosuppression suppresses the entire immune system, both the good (fighting infection) and the bad (transplant rejection). **Dr. Batty said, “It’s like using a sledgehammer to drive a thumb-tack.”** Doctors would like to just **selectively** shut down the “bad” functions and keep the “good” ones.

Bone marrow transplant is a standard treatment for multiple myeloma, a cancer of the bone marrow; this illness can also cause kidney failure. In the late 1990s, a patient at Massachusetts General Hospital received both bone marrow cells and a kidney transplant from a closely related relative with the happy result that immunosuppressive drugs were not needed long term. Massachusetts General Hospital, Northwestern University, and Stanford University started research on this finding in the early 2000s. They began with siblings who were “perfect matches” with all 6 HLA antigens identical.

When you get a kidney transplant, you are looking for a good “match.” There are 6 HLA (human leukocyte antigens) involved in matching kidneys with recipients; you get three each from your two parents. There is a 25% chance of matching all six HLA antigens with a sibling, a perfect match; 25% chance of not matching any of the antigens, and 50% chance of matching only 3 out of the 6 HLA antigens. Dr. Batty’s study is looking at the “perfect match.” **Each year, there are only about 325 sibling living donor kidney transplants in the U.S. with all 6 HLA antigens matching.**

How does the clinical trial work? Please look closely at the diagrams below:



# Medicare (continued from page 1)

## **What does ESRD Medicare cover?**

- All services covered by original Medicare
- Dialysis services
- Home-self dialysis training
- Home dialysis equipment and supplies
- Transplant and transplant preparation, plus lab tests, blood, organ procurement, and Transplant Network Registry fee.
- Full cost of donor care with no deductibles, coinsurance, or other costs to the donor
- Immunosuppressive drugs
- Medical nutrition therapy
- Hepatitis B shot
- Six kidney disease education sessions

## **What does ESRD Medicare NOT cover?**

- Paid dialysis aides
- Lost wages
- Housing during treatment
- Blood for home dialysis
- Non-treatment related medications
- All things Original Medicare doesn't cover
- Long term nursing facilities over 100 days
- Dentures and routine vision
- Cosmetic surgery and acupuncture
- Hearing aids and exams for fitting hearing aids
- Check [www.medicare.gov](http://www.medicare.gov) for other items

**Sign up** for Part A and Part B through the Social Security Administration, especially if you do not have employer coverage. With employer coverage, generally do not delay Part B without also delaying Part A, and don't miss the 30 month mark when Medicare becomes primary to an employer plan. ESRD Medicare ends one year after dialysis is no longer needed and three years post-transplant. Medicare assumes you can return to work and qualify for insurance. Afterwards, however, you can still have Medicare due to disability or age. Parts A & B have deductibles and copays; both parts are required to enroll in a Medigap or Medicare Advantage Plan.

**Medigap (Medicare Supplement Insurance) vs. Medicare Advantage (MA):** Medigap policies, sold by numerous insurance companies, pay Part A & B out-of-pocket costs. Medicare Advantage (MA) is an HMO plan, such as Kaiser, for example. However, MA Plans will not accept you with ESRD unless you already have that insurance's HMO through your company. Similarly, Medigap policies are still not available to those under 65 with ESRD. So, when you turn 65, it is a critical age in more ways than one! Timing is vital for Medigap coverage—don't wait!

For a **Medigap insurance** policy, contact your local private insurance company or broker. There are ten standard plans, A, B, C, D, F, G, K, L, M, N with F as the most comprehensive with no copays. You can also switch your Medigap plan, within 30 days of your birthday, to a plan of equal or fewer benefits; this does not require health screening. If you lose either your employer coverage or COBRA, you can immediately enroll in a Medigap Plan without health screening. Mr. Espiritu encourages us to review our drug plan each year (your needs may change) during the October 15 to December 7 Annual Enrollment Period.

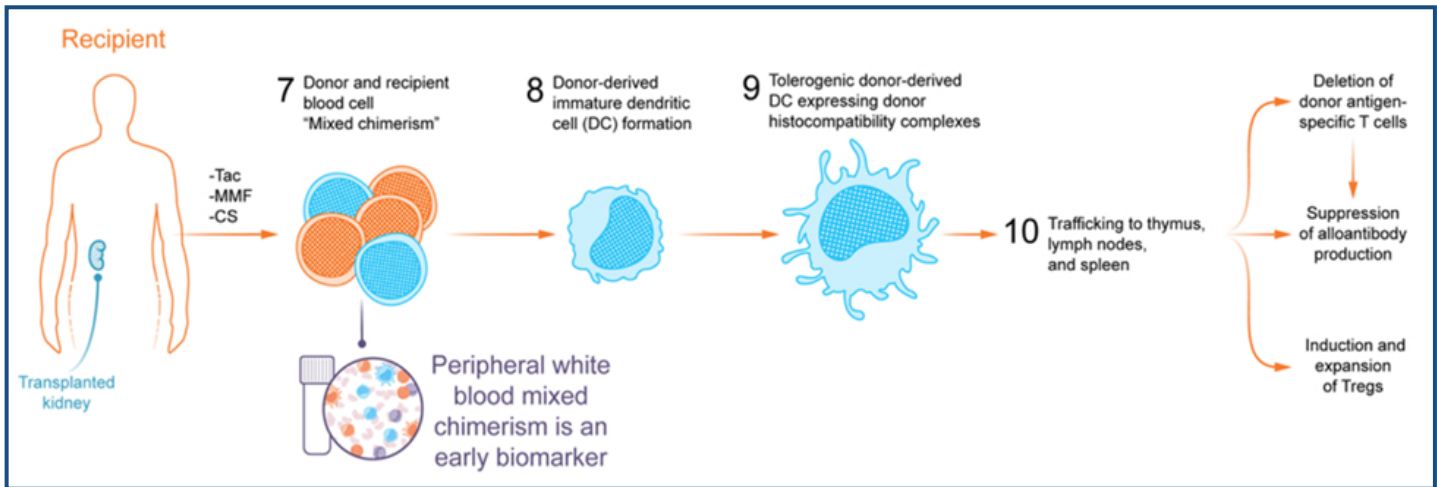
Mr. Espiritu included more information than we can include in this publication. Please refer to the BAAKP video, sponsored by Satellite Health, <http://www.baakp.org/video-archive-1.html> for details of Medicare A & B costs, deductibles, and eligibility; Primary and Secondary ranking of insurance plans and Medicare; Medi-Cal; Medigap; Employer Group Health Plans (EGHP); Supplemental Insurance plans; Medicare Advantage Plans; General Enrollment Period; drug coverage and more.

Thank you, Mr. Marcelo Espiritu, for your comprehensive presentation. You can be sure that our members will contact Sourcewise for help! (See Paragraph 2 for contact information.) And thanks to Medeor Therapeutics for sponsoring this Educational Presentation. ■

**The printing, postage, and website distribution of this newsletter  
is supported by a grant from the  
Palo Alto Foundation Medical Group Community Health Care Endowment Fund  
Thank you for your support!**

## Transplants without pills (continued from page 2)

At 6-7 months post-kidney transplant, the goal is that the subject (recipient of both the donor kidney and cells) will have a mixture of both donor cells, and recipient cells in the recipient bone marrow. Having both the recipient's cells and the donor's cells is called "Mixed chimerism"; this is the condition the researchers are hoping to achieve. As a result, the recipient will not reject the donor's cells as foreign, and the transplanted kidney will be recognized as "self" without the long-term regimen of immunosuppressive drugs!



Medeor Therapeutics has licensed the research and is seeking candidates for this clinical trial. For more information on this clinical trial, please visit: Website: <https://clinicaltrials.gov/NCT03363945> , Phone: 855-228-7517; Email: [mercury@medeortx.com](mailto:mercury@medeortx.com).

We thank Dr. Batty and his associates for bringing this valuable information to BAAKP. We also thank Medeor for their generous support of these two Educational Presentations. ■

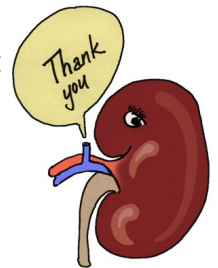
## Record Breaking Donations!

Thanks to the exceptional number of individuals who donated to the 2018 year-end fundraising, the Bay Area Association of Kidney Patients (BAAKP) raised \$10,952.40. With matching funds from a generous member, the total reached **\$15,952.40**. The BAAKP is grateful for the help of these individual donors, and looks forward to a great year! Now that you have helped, please let us know how BAAKP can help you.

Although thankful for the results of the individual year-end fundraising, it does not cover the total

yearly budget of about \$27,000. This financial gap is bridged by the institutional grants received in 2018. These grants were provided by Satellite Healthcare, Sanofi-Genzyme, Graftwerx, Palo Alto Foundation Medical Group Community Health Care Endowment Fund, and Medeor Therapeutics.

You expressed your belief in BAAKP, and BAAKP wants to help you to be an educated, supported, and confident kidney patient! ■



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

**Board of Directors:** Christie Chapman, Debra Elmore, Robert Neal, Linda Umbach, Walt Umbach, Marcus Wong, Phillip Wyche

**And to the many Speakers, Sponsors, and Volunteers**

**This issue is dedicated to Christie Chapman.** Christie joined BAAKP in 2014 and quickly became a vital, enthusiastic member of the Board of Directors. Since 2015, she was the editor of this newsletter. In addition, Christie served as MC at educational presentations and participated in panel discussions sharing her unique knowledge of insurance coverage for dialysis. Despite moving from California to Texas, she was always available to help others. We miss her greatly. RIP Christie.



# Education, Support and FUN!



## Bay Area Association of Kidney Patients



# The U.C. Davis Kidney Transplant Program

At our March Educational Presentation, we had the pleasure of having Eric Huang, M.D., M.S., Transplant Nephrologist, and Chief of the Department of Transplant Nephrology speak to us about the UC Davis Kidney Transplant program. Dr. Huang discussed the benefits of the kidney transplant program that UC Davis offers, and the best scenarios regarding patients' success rates.



Dr. Huang began by describing our kidneys and what they do. He said the kidney is a "smart" blood filter for transferring waste products into the urine. The "smart" kidney retains what the body needs, such as protein. A normal kidney filters 100cc of blood a minute. This 100 cc unit or ml is about a ½ cup or a total of 144 liters of blood which is filtered per 24-hour period. See chart for the stages of kidney disease relating to the ranges of GFR (Glomerular Filtration Rates).

## Glomerular filtrate rate (GFR)

- Chronic kidney disease
  - Stage 2 60-89 mL per minute
  - Stage 3 30-59
  - Stage 4 15-29
  - Stage 5 < 15
- Eligible for transplant waiting list: 20 ml/min

Please note that **you are eligible for the transplant waiting list when your GFR is 20 ml or cc/min or lower, long before dialysis begins.**

UC Davis is very supportive of **pre-emptive transplants** (getting a transplant before having to do dialysis). Those on dialysis, which is an incomplete process, can develop damage to the body such as accelerated atherosclerosis, malnutrition, and chronic inflammation. Dr. Huang described the advantages of this **Pre-Emptive Transplant**, which occurs in only **2.5% of ESRD** (End-Stage Renal Disease) patients!

**Why doesn't Pre-Emptive Transplant happen more often?** Kidney problems may be discovered late; there could be a rapid progression of the kidney disease or the lack of living kidney donor. (Editor's Note: or patients are unaware of preemptive transplant.) When the GFR drops to 30, it's time to start thinking about a transplant, preferably with a living donor, and getting referred to a transplant center.

The UC Davis Kidney Transplant Program has transplanted more than 4,000 kidneys and averages 250-300 kidney transplants per year. UC Davis is in a separate OPO (Organ Procurement Organization) because it is the only transplant center in its region, see map. You can only register at one transplant center in each OPO, for example, at Stanford and UC Davis, (which are in two OPOs) not Stanford and UCSF (which are in the same OPO.)



And, unlike most other transplant centers, UC Davis can reduce waiting times because they use "non-conventional" kidneys other transplant centers may refuse. All donor kidneys are rated according to the donor's medical conditions and/or cause of death. The donor kidney is screened and will be ranked by the KDPI index, scored from 0 to 100 KDPI, with the higher indexes indicating the kidney may not last as long, but enables patients to receive a transplant and get off of dialysis. At 6 years, 50% of the high (86-100%) KDPI kidneys are still functioning!

For the ultimate success for an early kidney transplant, Dr. Huang urges you to:

- Get diagnosed early
- Start thinking about a donor promptly
- Find possible live donors – preparation and registration of donor are required

(Continued on Page 7)



## U.C. Davis Kidney Transplantation (continued from page 6)

UC Davis boasts the shortest waiting times in Northern California, sometimes with ¼ of the listed patients getting a transplant within a year! And in 3 years, 45% of those listed have received a transplant! The length of time you may have to wait to get a kidney (from the time you get on the waiting list) depends on many factors including your blood type, your overall health, your ability to tolerate surgery, and ability to take immunosuppressive medications. Because of their short wait times, UC Davis emphasizes readiness for transplant. Thus, before "listing," the patient must complete all testing for



- Cardiac disease
- Vascular disease
- Infectious disease
- Cancer
- Physical activity performance (ability to climb 3 to 4 flights of stairs)
- Independence with activities of daily living
- Financial and insurance qualification

Dr. Huang again emphasized that pre-emptive kidney transplantation (before the initiation of dialysis) is optimal and has a direct relationship to the life of the transplanted kidney and patient's quality of life. Plus, if you bring a living donor, UC Davis will expedite your transplant, often within 3 months.

According to Dr. Huang and the staff at UC Davis, when you want a transplant, remember that the:

- Shorter time on dialysis is ideal;
- Preemptive transplant is the best;
- Shorter waiting time at UC Davis than other California Transplant Centers
- Use of non-conventional kidneys reduces waiting time.

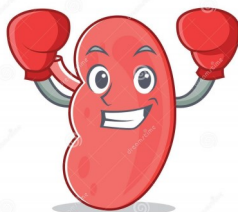
Thank you, Dr. Huang, for your very complete review of kidney transplantation at UC Davis. To contact the UC Davis kidney transplant center, call 916-734-2111 or 800-821-9912. Their web page is at <https://health.ucdavis.edu/transplant/newreferral/kidney.html>. Thanks to Medeor for your support. To see a video (sponsored by Satellite) of this presentation, go to <http://www.baakp.org/new-videos.html>. ■

### Kidney-versaries!!

The Bay Area Association of Kidney Patients recognizes our members who have worked for and received a kidney transplant. If you would like your name and your transplant date in a future newsletter, please let us know the date of your transplant. **YOU ROCK!**

650-323-2225

[info@baakp.org](mailto:info@baakp.org)



Rebecca Sidor	February 7, 2001
Linda Umbach	February 27, 2008
James Hoey	April 21, 2010
Karen Soo Hoo	February 11, 2014
Christine Sleight	April 14, 2016
James Billbury	May 27, 2016
Pam Mery	March 6, 2018
Rachel Eaton	April 24, 2018
Craig Elliott	September 29, 2018
Israel Shualy	January 14, 2019



# Bay Area Association of Kidney Patients

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

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



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

## ***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 14, 2019
- October 2, 2019

## ***East Bay Events***

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

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

- August 11, 2019
- November 17, 2019

## ***San Francisco Events***

California Pacific Medical Center  
Van Ness Campus  
21101 Van Ness Avenue, San Francisco

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

- September 8, 2019
- December 8, 2019

## ***Board of Directors' Meetings***

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

## **Your Labs & Meet the Renal Warrior!**

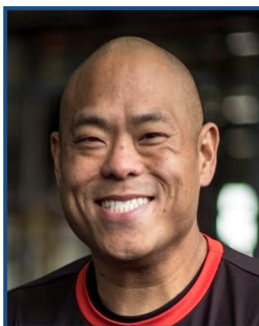
Mark your calendars for our next Educational Presentation on  
**Sunday, September 29, 2019**, from 1 to 3 pm! We are returning to  
our Palo Alto location, 795 El Camino Real, 3rd floor, Palo Alto, CA  
94301. Save the date for this **FREE** event.

**Mitra Sorooshian, M.D.**, Director of  
Nephrology at Palo Alto Medical Foundation  
(PAMF,) Mountain View, will discuss the many  
**laboratory tests** we must take as patients.

### **Bring your laboratory**

**reports** and questions on  
this important topic!

Our second speaker will be  
dialysis patient, **Wilson Du,**  
**the Renal Warrior**, with an  
inspiring story of how his life changed after being  
diagnosed with End Stage Renal Disease in the  
emergency room.



### **To Register:**

<https://tinyurl.com/BAAKP-Sept2019>.

You can also phone 650-323-2225 or  
email us at [info@baakp.org](mailto:info@baakp.org).

### **Sponsor**

