

An Altruistic Donation

By Clarence

This is the story that Clarence wrote about his altruistic kidney donation to a stranger. Rebecca was the lucky recipient of that noble decision!

I first heard of living donation through watching a TED talk by Ned Brooks. He spoke of learning about altruistic kidney donation from a podcast and immediately knew he would donate a kidney to a stranger. I had the same reaction upon hearing his talk. I thought:

"This is something I could do, something I want to do, and this is something I will do."

After discussing it with my partner, I decided to move forward with the process. We had recently moved to the San Francisco Bay Area and had one of the country's best transplant departments in our backyard. I contacted UCSF and went through the initial testing. The process was extremely meticulous, and I fully felt that UCSF had my best interests at heart. I was going through the process to get matched with a stranger through the hospital network, when I mentioned my plans to donate to my sister-in-law, Molly. She told me about a friend of hers, Rebecca, who she had had lunch with the day before. Rebecca needed a kidney.



Rebecca and I moved forward with testing to see if we were a match, and we were! June 23, 2020, was the date scheduled for the surgery.

The team of surgeons was excellent and took every effort to explain the process, the healing, and put my mind at ease. I was able to go home three days after the surgery, and two weeks later, I was feeling back to my usual self.

Now, a year-and-a-half later, I feel physically and mentally healthy. I feel proud and fulfilled knowing that a small piece of my body is living on in another human and making it possible for Rebecca to continue to live out her life fully and be a positive influence in the world. **Editor's note:** The TED talk link is <https://youtu.be/nhht9kslq04>

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The Bay Area Association of Kidney Patients

is a volunteer non-profit 501(c) 3 organization with the

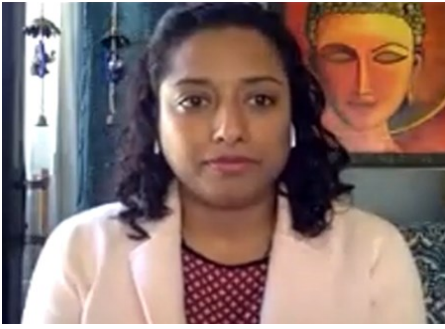
Mission to Educate and Support Bay Area Kidney Patients

Attend the Educational Presentations and Support Group Meetings, read the *Kidney Connections* newsletter and visit our website at www.baakp.org



Kidney Konnections

How to Maintain Your Kidney Transplant



On June 27, 2021, we were honored to have Dr. Neha Garg, MD, MPH, a transplant nephrologist from the California Pacific Medical Center in San Francisco speak to us about

how to maintain your kidney transplant. CPMC performs approximately 200 kidney and kidney-pancreas transplants each year. Dr. Garg has been a full-time transplant nephrologist at CPMC for 5 years. She sees renal patients in the Bay Area, Redding, Modesto, Fresno, and Roseville.

Dr. Garg noted that survival rates for transplants performed in 2008–2015 are: A 1-year survival rate after a kidney transplant of 93.2% for those with cadaveric donors and 97.5% for those with living donors. At around 5 years, the rate declines somewhat with about 75% survival rate at the end of five years for cadaveric donors and 85% for kidneys from living donors. Dr. Garg went on to discuss the following:

Early graft loss is defined as the failure of the kidney graft within 1 year of transplant. This is an uncommon occurrence. The incidence of graft loss in the first year is only between 3% to 7%. Early failure can be because of surgical or mechanical failure. Renal vein thrombosis is one of the more common surgical complications within the first year. Renal veins from a cadaver donor are often prone to injury. A slight kink or a blood clot can also lead to failure of a kidney graft. Primary non-function due to injury when kidneys are taken from a cadaver donor, early rejection, BK virus infections and other infections are some of the possible causes of early graft loss.

Late graft loss is the loss of the kidney allograft more than one year from the transplant involving a combination of donor and recipient factors and depends on age, ethnicity and medical history. A late graft loss can be from a slow progressive decline as a result of an early rejection, late rejections, recurrence of primary disease (diabetes, glomerulonephritis), viral infection (BK virus), diabetes (old and new onset), cardiovascular risks and other illnesses that cause recurrent acute kidney injury (such as severe infection, chronic diarrhea, or malignancy).

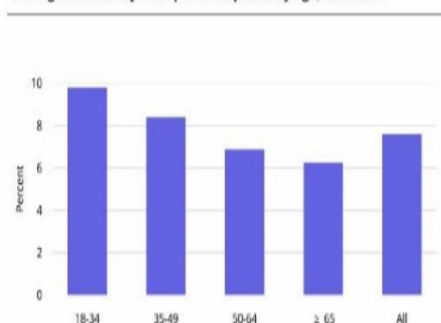
How does a rejection present? The majority of kidney rejections tend to be completely asymptomatic. The best way to detect rejection early is by performing frequent routine laboratory tests. The most important lab tests to monitor are the serum creatinine (the main marker for your kidney), tacrolimus or everolimus levels (medicines that are dosed according to the target drug level) and urine protein (shows kidney injury). There is also new test (cell-free DNA panel) that is helpful in detecting oncoming rejection and is now used in many centers as part of routine follow testing for long-term follow-up.

It is extremely important that in the first year, all patients learn how to interpret their own labs.

Infections can be a cause of kidney rejection. These include urinary tract infections, upper respiratory infections, severe pneumonias, BK virus infections, reactivation of shingles and tuberculosis infections, and endemic infections (like Valley fever and Nocardia in Central Valley of California). During the first 3-6 months after transplant, recipients are given prophylactic antibacterial, antiviral and antifungal medications so these infections are rare. Infections are often seen after prophylactic medications are stopped.

How do you prevent infections? Good nutritional status is a must! Good hand hygiene and avoiding crowded places in the first 4-6 months after transplant are crucial. Anyone who has had a history of a prior serious infection (like tuberculosis, valley fever, and other fungal infections) needs to let their transplant doctor know because a longer period of prophylactic antibiotics will be required. Be sure get all vaccinations prior to transplant. For any prostate or urinary retention issues after transplant it is important to get a timely urology consult and follow-up.

Figure KI 97. Incidence of acute rejection by 1 year posttransplant among adult kidney transplant recipients by age, 2016-2017



OPTN/SRTR 2018 Annual Data Report

Rejection risk in 1st year post transplant

- 10% risk in age 18 - 34 years
- 8% risk in age 35 - 49 years
- 7% risk in age 50 - 64 years
- 6% risk in age over 60 years

Up to 8% risk of acute rejection during 1st year but graft loss from rejection is very rare in the 1st year.

Higher risk of graft loss from late rejections (> 1 year from txp)

How to Maintain Your Kidney Transplant *(continued from Page 2)*

Drug adherence and stable drug levels are crucial in preventing rejections.

Diabetes is the biggest risk factor for kidney failure. Currently, diabetes contributes to 50% of cases of end-stage kidney failure before and after transplant. In a lot of kidney biopsy studies, within 5 years, diabetic changes can be seen in the new kidney graft. It is why a strict control of blood sugars is extremely vital. On the other hand, **Cardiovascular** risks accelerates the aging of the kidney. To manage this risk, it is important to maintain control of your blood pressure. It is also important to tailor the immunosuppression therapy. For those who do have sleep apnea, CPAP is very necessary. CPAP clears airway obstruction and reduces the nighttime blood pressure.

Cancer risks goes up when the immune system is suppressed. The immune cells are also the body's cancer-fighting cells. Skin cancer accounts for 40% of post-transplant malignancy. The risk is higher in older recipients. It is higher in people working out in the fields, agriculture or landscaping and places with heavy sun exposure. Sunscreen and protective clothing is a must. The risk of recurring malignancy is higher in those with

prior history. Routine cancer screenings such as pap smear, mammogram, colonoscopy, and prostate testing as recommended for any age group should continue as well as follow ups with your primary care provider.

What are some of the dietary recommendations? For diabetics and renal diet, the best foods to eat are vegetables. Vegetables have low sugars and low carbs. Except for green peas, most of the other vegetables don't have a lot of starches. Potatoes and corn are starches and should not be counted as vegetables. Many fruits are high in sugar. A low salt diet is optimal for controlling blood pressure. A diet low in preservatives and packaged foods helps prevent metabolic syndrome, insulin resistance and weight gain. Avoid excessive protein supplements (GNC powders, protein shakes, energy drinks). Excessive proteins increase the work-load of the kidney. Eat less red meat, and more lean white meats.

Get moving! An active lifestyle is very important. Exercise helps with both your physical and mental well-being.

For more information and to view Dr. Garg's presentation, please visit the BAAKP website.



Follow us on
Instagram



@bayareakidney

***The Bay Area
Association of Kidney
Patients (BAAKP) is
now on
Instagram!!!
Check it out!***

A Gift That Keeps On Giving

- A story by Denise Ray



In 2014, I was working two jobs and doing long commutes. It was a stressful time in my life. My body began experiencing fatigue, extra fluid buildup, and increased blood pressure. I thought about seeing a doctor but I didn't. Unfortunately, I failed to listen to what my

body was telling me. One day, while at work, I passed out and was taken to a hospital emergency room. I was examined and a blood test revealed that my kidneys were failing and that I needed to consider kidney dialysis or a kidney transplant (at the time, the wait time for a transplant was approximately 8 years). I was scared and confused. At that time, I refused to start dialysis because if I started dialysis then I would need to take a leave from work. I wanted to continue working and I was hopeful that I would get better with rest. I continued to work and manage my blood pressure and diabetes. This routine went on for about four years.

I changed to a private Nephrology Clinic located in Redwood City, California under the care of Dr. Ng. Our patient and doctor relationship did not start very well as I was still in denial. He was straightforward with me about my kidneys, weight, and diabetes. During one of our appointments, Dr. Ng explained to me what my life would be without dialysis. We discussed the types of dialysis available and the possibility of a transplant. I was still very scared but I thought about my children, family, and friends. They are very important to me. With my failing kidneys and high blood pressure, I was not in my best physical condition. I knew at that moment it was time. In 2018, I was placed on the transplant list with Dr. Day's kidney transplant team at UCSF and I started doing home peritoneal dialysis.

I worked hard in maintaining my treatments. I kept a positive attitude and energy despite having fear of how long I would be in this condition

waiting for a kidney transplant. I began to think of all the moments I have with my children and how I look forward to having grandchildren someday.

Since I work in the field of mental health, homelessness, and displaced families, I had to take off from work during the pandemic. One day as I was doing a dialysis treatment, I decided to make a video for my family. I did it to share my love and words of kindness with them. A relative who saw the video reached out to me and told me that they knew someone that belonged to a Bay Area kidney support group that could help me. They told me to contact Mr. Phil Wyche from the BAAKP which I did. During my first conversation with Phil, we shared dialysis stories and experiences. I learned of ways to better educate myself on kidney failure and dialysis treatments. It was the best call I ever made. I became a better dialysis patient and decided to navigate this dialysis journey for "ME."

On August 19, 2020, I received a call from UCSF for a kidney transplant. I received my kidney from a deceased 18-year-old person. My transplant was a complete success. It is a new gift of life that I am so fortunate to have. Now I am ready for the world. My determination to push through the difficult times is now behind me. A few months after my transplant, my grandson was born, I returned to work and I felt great. I couldn't have done it alone. Many individuals assisted me through this journey that changed my life. I share what I learned traveling this winding road, knowing that there are people who want to help kidney patients. With so much change happening in the world of kidney failure, support groups are so valuable.



A Gift That Keeps On Giving *(continued from Page 4)*

I am so fortunate to have this new gift of life. Now I am ready for the world.

I learned so much from the Bay Area Association of Kidney Patients (BAAKP) support group and it's wonderful to give back in so many ways. So to celebrate my birthday on May 23, 2020, I decided to set up a fundraising campaign on my Facebook page.

With my most high gratitude and faith I honor these special people:

- My sons Evan, and Joseph for their years of nurturing and Love,
- UCSF Dr. Day Kidney transplant department
- Joyce and Mila: Davita Dialysis Center
- Dr. Phillip Ng and Dr. Charlotte Gonzales: Private practice—Nephrology
- LaRaea Ford: Catering
- Laverne Williams: 20 years family friend



NOTE: If you would like help in setting up a BAAKP fundraising campaign on your Facebook page, contact Debra Elmore at debra.elmore@baakp.org for our logo.

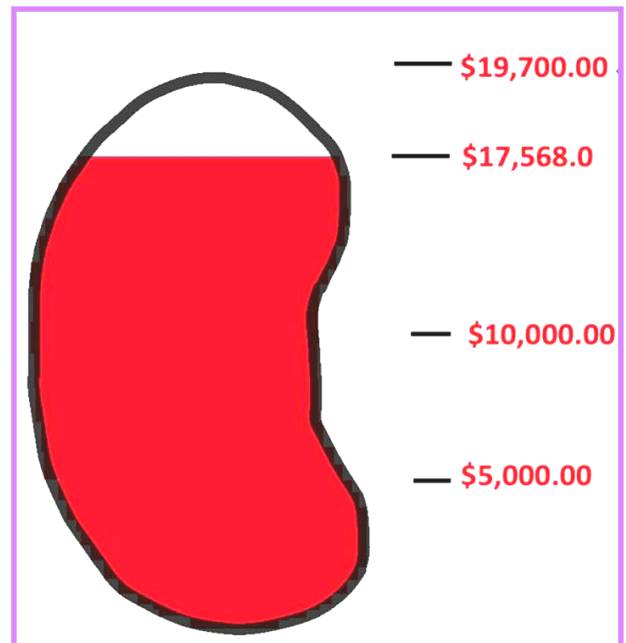
We Did It! Thank You For Your Support!

Results of the Fundraising Campaign that began on #GivingTuesday 2021

Thanks to the many donors (60 this year), the Bay Area Association of Kidney Patients received \$17,618.00, with the average donor contributing \$293.63 — much higher than last year. The BAAKP is grateful for the help of these individual donors and looks forward to a successful 2022!

The Pandemic created a challenging picture for all non-profits, but BAAKP rallied to raise donations to continue our remote educational meetings and support groups. Life is indeed different, but patients with kidney disease are not different. They need support and education to fight through the maze of medical visits, treatments, and "Oh! What do I do next?"

Your donations expressed your trust in BAAKP, and BAAKP wants to help kidney patients be educated, supported, and confident. Now that you have supported BAAKP, please let us know how BAAKP can support you!



Expanding Our Reach

The BAAKP was fortunate to get to know two new kidney support groups in 2021 – one in Florida and the other in Maryland! Both groups are still meeting virtually so some BAAKP members have been able to attend their monthly support groups.

The first group is **All Kidney Patients Support Group** (AKPSG). AKPSG was founded by Janice Starling in 2009 and is located in St. Petersburg, Florida. Their mission is to support kidney patients at various stages of dialysis and transplantation to live a quality life. Their support group meets the last Sunday of the month at 12:30 PST. Each support group meeting features a speaker/topic. AKPSG also offers free kidney friendly food distribution on the second Tuesday of the month.

The other group, **Kindness for Kidneys International**, was founded by Sharron Rouse in 2018 and is located in Maryland and serves the Washington, DC metropolitan area. Their mission is to educate, encourage and empower kidney warriors and their families. They had their first in-person support group in 2020 right before everything shut down because of COVID. They quickly pivoted to Zoom support group meetings on the 2nd Sunday of the month at 12:30 PST. They

also had a COVID-19 Lunch on Us Program where they brought lunch to dialysis clinic workers during the pandemic. Their Kidney Conversations program facilitates bringing families together to discuss kidney disease and/or organ donation.

In December, BAAKP joined AKPSG, Kindness for Kidneys, the American Association of Kidney Patients, and the National Kidney Foundation of Florida for a "5-in-1 Holiday Fun" holiday party via Zoom. Each organization introduced themselves and then the games began: kidney trivia and a scavenger hunt! Fun was had by all, and prizes were awarded to the top three winners in each game. Prizes included Amazon gift cards, a blood pressure machine, and "swag" boxes from the different support groups represented (coffee cups, t-shirts, baseball caps, masks, chargers, calendars, recipe books, etc.)

We are so grateful to have become "friends" with these other kidney support groups and look forward to learning and sharing with them to benefit the kidney community no matter where you are located.



www.kindnessforkidneys.org

Meets the 2nd Sunday of the month at 12:30 PST

kindnessforkidneys@gmail.com



All Kidney Patients Support Group

Akpsupportgroup.org

Meets the last Sunday of the month at 12:30 PST

akpsg@earthlink.net

The Three-Way Cross Country Kidney Swap That Almost Didn't Happen

In 2007, Tomomi Barron wanted to donate a kidney to her husband, Patrick. The problem was, she wasn't a match. Patrick suffered from kidney failure due to a genetic disorder (Polycystic Kidney Disease). They traveled to various hospitals to get on a shorter waiting list and even thought about traveling to China, where foreigners could get transplants quickly. Then, luckily there was a match for a paired exchange here in the Bay Area.

Next the Barrons got a call from Johns Hopkins in Baltimore, which they had visited. Tomomi's kidney was a rare match for one of Dr. Montgomery's patients. She could not find another match, and things weren't looking good. A native of Japan, Tomomi was impressed by the culture of volunteering in her new country, and she was determined to go the extra step and donate her kidney to the woman who seemed almost impossible to match.

Johns Hopkins physician Robert Montgomery, MD, a pioneer in kidney paired donation, initially suggested a three-way cross-country swap among donors, inserting his hard-to-match patient, a Maryland resident, into the mix.

Patrick was not comfortable with Tomomi, who was non-native to the US, having to travel alone for a surgery and simply wanted to go with a local donor swap. Dr. Montgomery, disappointed initially, came back with a bolder and more elegant proposal, to fly donor kidneys to their recipients, allowing donors to stay with their families. Instead of Tomomi physically traveling alone to Johns Hopkins, Dr. Montgomery achieved a cross-country transplant, where both donor and recipients would stay in their home cities, while the kidneys did the flying. Tomomi's kidney flew in a refrigerated pack to his hospital and was transplanted to the recipient.

Tomomi's determination to help both patients, combined with Dr. Montgomery's creativity, helped pioneer cross-country, multiple paired kidney transplants. It was not only a gift to all the three patients in this exchange but to future kidney donors and recipients as well. Patrick's and the other kidney recipients' transplants were pioneering efforts to search the U.S and utilize different hospital systems working together to ensure the best patient outcomes.



Patrick & Tomomi

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Educating & Supporting Kidney Patients!

Please visit our website at

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!



Support Group Meetings

Due to Covid-19, all in-person BAAKP events (Education Presentations and Support Groups) are held online until further notice. Meetings are usually the 2nd Sunday of the month from 1-3 pm. You can register online at <http://www.baakp.org/calendar.html> to attend a meeting.

Dates for Upcoming Zoom Meetings:

- March 13, 2022**
- April 10, 2022**
- May 1, 2022**
- June 12, 2022**
- July 10, 2022**
- August 14, 2022**
- September 11, 2022**
- October 9, 2022**
- November 13, 2022**
- December 11, 2022**

