

A Kidney Transplant at Last!



Bay Area Association of
Kidney Patients

Kidney Konnections

In December 2005, I discovered that my blood pressure was higher than I expected when I tried the blood pressure monitor at a drug store. I thought it was temporary, because my blood pressure was usually of an average level. My blood pressure stayed high so after several months I decided to take the medicine prescribed by my primary care physician. This medicine controlled my blood pressure well and I went on to lead my busy life. By Fall 2015 however, my kidney function had fallen below the normal range. I was told to see a nephrologist. An ultrasound showed that both my kidneys were enlarged and had numerous cysts. I was diagnosed with a hereditary disease called Polycystic Kidney Disease (PKD). I probably inherited it from my mother, who passed away at the age of 39 when I was 11 years old. (Thinking back, my high blood pressure was the first symptom of PKD.)

Unfortunately, there was no medicine to treat PKD at the time. All I could do was stick to a kidney friendly diet and live a healthy life style. Even so, my kidneys continued to deteriorate; my Glomerular Filtration Rate (GFR) dropped from 50-60% to 30% within a year of being diagnosed. "You have a very progressive type of PKD," my doctor said, and I was referred to Dr. Meyeon Park at the UCSF PKD center

in January 2017. In March 2018, my GFR decreased to 20%. That's when I decided to quit my beloved job as a clinical lab scientist. I needed more time to pay attention to my health. At Dr. Park's suggestion, I applied for the kidney transplant program at UCSF. After being interviewed, then completing many tests, I was put on the wait list.

By November 2018, I was not feeling well. I was anemic, tired, and feeling nauseous from time to time. I knew it was time for dialysis. Since I wanted to go to a nearby dialysis center, I needed a local nephrologist. Dr. George Ting at El Camino Renal Group became my nephrologist. He was truly experienced, knowledgeable and kind. He told me what I already knew: I needed dialysis as soon as possible. I chose WellBound Dialysis Center in Mountain View, and I decided to do peritoneal dialysis (PD), as it preserves remaining kidney function better than hemodialysis and is gentler on the body. I started doing PD at home in February 2019.



Pearl Su

(Continued on page 4)

In This Issue...

<i>A Kidney Transplant at Last!</i>	pg 1
<i>Chain of Events & Prepared for Dialysis</i>	pg 2
<i>Dialysis is NOT "for the Birds"</i>	pg 3
<i>You Did It! Thank You!</i>	pg 4
<i>Just Keep Pushing</i>	pg 5
<i>Zoom Support Group Meetings</i>	pg 5
<i>My Mom and I, We're a Team</i>	pg 6
<i>I've Got Your Back</i>	pg 7
<i>BAAKP Webinar</i>	Pg 8

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

Edited by Ryan Madison

Chain of Events

Polycystic Kidney Disease runs in my family. I was diagnosed at age 46. My father & brother were diagnosed much later in life and succumbed to it at 74 and 65. After reaching just 10% kidney function, I was on dialysis for almost a year: in-center hemodialysis at first, and home peritoneal later.



Alan Lapp

I received a spot in a chain transplant with 4 donors and 4 recipients at California Pacific Medical Center (CPMC) in San Francisco. The Matron of Honor from our wedding was my donor, and we joked that it was marriage warranty work.

Throughout all this, we were grateful for the BAAKP monthly meetings as a resource for information and reassurance from its experienced members.

Thanks to this miracle of science, 4½ years later I feel good and energetic. My wife and I run our own graphic design & medical/science illustration business. We recently revamped our site (levelfive.com) and are diving into a new business push.

When I got sick, I stepped down from the board of the South End Rowing Club because of dwindling energy. Post-transplant, I was pleased to be capable of – and re-elected to – board service.

While I am focused on our business, my passion is motorcycling. I've completed three custom motorcycles – one received national attention and was invited to multiple shows. I also enjoy socially-distant moto-travel and camping with friends all over California. None of which would be possible without all the help I received from BAAKP and the wonders of modern medicine.

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

Prepared for Dialysis

Bertha Dickerson has a different story to tell. She lives in Oakland and, for many years, commuted by public transportation to San Francisco for her job as a social worker; a position she loved. She was an only child, with her father passing away when she was a young girl, and her mother who passed several years ago. Both parents had diabetes and Bertha is diabetic as well. In 2009, her primary care physician found protein in her urine and referred her to a nephrologist and nutritionist. She learned much from the nutritionist but found that the nephrologist didn't explain things well at all.

Bertha knew it was essential to understand kidney disease and discovered the BAAKP Oakland support group in 2014. She left her job around 2011 and missed it, but she felt she had to concentrate on her health. The BAAKP support group meetings filled a need to connect with others who were traveling the same road. At the same group meetings, she learned about Dr. Ole Dierks, a nephrologist and a medical advisor for BAAKP; he is now her nephrologist.

One of the benefits of belonging to a group is learning of others' life experiences and solutions. She calls this "group knowledge."

In July 2020, Bertha started in-center hemodialysis, three days a week, 4 hours each time. Bertha says,

"It's not as horrific as I thought it would be."

Needless to say, over the years, she had learned much about dialysis from the many support group meetings she attended and was well prepared for what life had thrown her way.



Bertha Dickerson

Dialysis is NOT "for the Birds"

By Ken Roman, 91 year old dialysis patient

About being dialyzed...

Learn to be happy and grateful for the "gift of dialysis." There are many body failures, without any solutions.

Fortunately, when kidneys fail there is dialysis.

Dialysis is not "for the birds" ... Dialysis, is for humans like you and me!



Dialysis is paid for by Medicare and supplemental insurance, or by commercial insurance. All one has to do is be willing to devote three days a week for this painless procedure.

When you commit to the rigorous routine of being dialyzed, in return, you're given the greatest Gift one can receive... **The gift of life!**

The goal of life is to be happy in the world, so that you can enjoy the "choices" offered when alive. The life of a bird is so much simpler than a human. When you accept the fact that you are not a "bird", but are simply a human being, then you are prepared to use all the means of humans have, to adjust, develop, and be Happy!

The Key to being happy with dialysis... is learning to be grateful and developing a wide open-mind that is willing to adjust, to the lifestyle changes that dialysis creates.

THINGS TO BE GRATEFUL FOR...

- Be grateful for yourself and your loved ones. It is your loved ones who want to share their lives with you.
- Be grateful for all the trained personnel ready and willing to do what has to be done to keep you going as a human.
- Be grateful for the doctor's, nurses, social workers, nutritionists, technicians and all the supply people that make it possible for you to be dialyzed.

THINGS TO ADJUST TO...

- One must learn how to adjust to the "lifestyle changes" from being dialyzed on a demanding schedule. Dialysis requires a complete adjustment to one's lifestyle. When you committed to the routine of being dialyzed 3 days a week, your lifestyle dramatically changed. Keep in mind the alternative!
- On the other hand, when you can no longer take care of yourself, you have the privilege to say, "No more dialysis." In short order, you are history. You have chosen an easy way to depart this world, saving your loved ones the tasks of attending to someone that's not able to take care of themselves. This is not an easy thought to "make peace with." If you ponder this thought over a period of time, you may see its value and see it as another reason to be grateful for your dialysis. If you take the time to study the thoughts above you may be able to actually love your dialysis. When you are in love, you are happy, and being happy is one of the goals of being alive!

Other Kidney Resources — Check our website at www.baakp.org for more!

American Association of Kidney Patients AAKP

14440 Bruce B.
Downs Blvd.
Tampa, Florida 33613
(800) 749-2257

www.aakp.org

Valley Renal Support Group

Covering the Central Valley
between Fresno
and Bakersfield

Contact: Maria Grijalva
Phone: (559) 688-6804

Email:
grijalvamaría@icloud.com

Transplant Recipients International Organization (TRIO)

2nd Thursday of each
month at 7:00 pm,
currently via Zoom

Email: bayarea-trio@gmail.com
www.bayareatrio.org

The National Kidney Foundation

131 Steuart St Ste 425
San Francisco, CA 94105
www.kidneyca.org

(888) 427-5653

www.kidney.org

A Kidney Transplant at Last! *(continued from Page 1)*

From BAAKP's support group, I learned that one could sign up with a second transplant center in a different region. At a BAAKP sponsored education event in March 2019 I heard Dr. Huang's presentation about UC Davis' transplant program and I decided to apply to UC Davis transplant program as well.

On Feb. 10, 2020, near noontime, "the call" came from UC Davis — there was a potential kidney offer for me from Louisiana. If I accepted the offer, they would arrange to transport the kidney to UC Davis. Initially I was a little hesitant. It would take 5 to 6 hours by air to deliver the kidney to UC Davis. I wondered if being on ice so long without perfusion might do some damage to the kidney. Not to mention that the KDPI score was not as ideal as I would have liked it to be. On the other hand, I clearly understood my situation: 1) I was 66 years old and had been on dialysis for a year. It was best for me to receive kidney transplant soon while I was still relatively healthy, 2) I had a high antibody level (83%), which made it hard to find a match for me at all. After calling Dr. Ting and my dialysis nurse, Judy, I accepted the offer. With their encouragement, my husband and I felt confident and headed to UC Davis Medical Center.

The next morning at 3 am the transplant operation began. Afterwards I had a case of delayed graft function which means the kidney didn't start working right away. Dr. Perez assured me it was a good kidney and it just needed more time to wake up and I needed to be patient. He was right! What A Joy!

Life without dialysis is so wonderful, as if I got a bit of my old life back. So many people helped me on my way to regain my health. I am forever grateful to my kidney donor, Dr. Perez, and the UC Davis transplant team for giving me a new kidney (and a new life). I appreciate my dear husband who supported my journey to gain my health back. From the bottom of my heart, I also thank Dr. Ting who took good care of me, prepared me well for kidney transplant and gave me great guidance. I can't forget the staff at Well-Bound in Mountain View, especially Judy who helped me a great deal while I was on dialysis, and my wonderful family and friends. Last, but not least, BAAKP which offers support for patients in all stages of chronic kidney disease. With its support and valuable resources, my journey toward kidney transplant and to get my health back was not lonely. Thank you, BAAKP!

You Did It! Thank You!

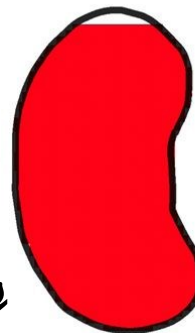
Thanks to the many donors who supported our 2020-21 Yearly Fundraising Campaign, the Bay Area Association of Kidney Patients (BAAKP) raised **\$18,359.42**. We much appreciate the over-the-top efforts of our donors and BAAKP Board Members. And with a \$5000 matching donation from a generous member, the total reached **\$23,359.42**. The BAAKP is grateful for the help of these individual donors, and looks forward to a great 2021! The Pandemic created a challenging picture for all non-profits, but BAAKP rallied to raise more donations than ever before!

Your donations expressed your trust in BAAKP, and BAAKP wants to help you to be an educated, supported, and confident kidney patient! Now that you

have helped BAAKP, please let us know how BAAKP can help you.

**We Thank You All
For Your Generosity!**

*You Did It!
Record-Breaking
Donations and
Number of Donors*



— \$24,000.00 Goal
— \$23,359.42 Feb 15, 2021

— \$12,000.00

— \$6,000.00

Just Keep Pushing

Viveca Jones, a resident of Berkeley, California, is a mother, grandmother and community supporter for the homeless. It was from her father's family background, however, that she inherited kidney disease. She was on dialysis for 4-1/2 years and was an entertaining attendee at BAAKP Educational Presentations. She received a kidney transplant in June of 2016, then in 2019 had a stroke which resulted in three brain operations. She lost her eyebrows and lashes and became deaf in one ear. She said, "I was dead and knew what it was to be dead. They saved my life!"

The pandemic has been devastating to many, and Viveca has lost 11 relatives and friends since January 2020. "I feel blessed to be still alive and well. I eat healthy (protecting the gift of life, my kidney) and continue to work one day a week. I spread the word about kidney disease and dialysis whenever I

can. I never stop talking about the dialysis treatment modalities available for everyone."

Viveca advises you to "be your own doctor – get out and walk and ride bikes."



"I give back to those in my community by feeding the homeless twice daily. I feel it is vital to make sure there is an adequate food supply for those who cannot get to a food pantry. I help with sandwiches, fresh salads and fresh fruit that I gather from neighbors' fruit trees (oranges and apples) instead of letting them go to waste. Food from the food bank goes into boxes for those who may pass by my house to pick up for free. Helping others keeps me going."

Support Group Meetings

Due to Covid-19, all in-person BAAKP events (Education Presentations and Support Groups) are held online until further notice. We started having our monthly support group meetings online via Zoom in March. 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.

Upcoming Zoom meetings are:

- March 14, 2021
- April 11, 2021 (Webinar)
- May 16, 2021
- June 13, 2021
- July 11, 2021
- August 8, 2021



“My Mom and I, We’re a Team”

My name is Toni Rodolfo-Benson and I was recently approved by CPMC to be a living kidney donor for my mom. I am thrilled that my mom and I match and will go through this part of the journey together.

My mom is 74 years old and she’s had chronic kidney disease for many years now. I remember the day my mom told me that she had kidney disease and may need dialysis. It felt like a death sentence. I cried. I was so afraid. I had so many questions. I started reading about my mom’s disease and how I could help her through her journey. I wanted to know how I could support her and help her navigate the healthcare system. Our family suspects that her kidney disease was brought on by a combination of her hypertension, gout, and taking high doses of ibuprofen for a prolonged period. My mom has lived a healthy life. She ran marathons and enjoyed ballroom dancing in her younger years. She loves food, but she’s always maintained a healthy weight.

I inherited my active, healthy lifestyle from her. I run, do yoga, meditate and eat a healthy diet. As it turns out, diabetes actually runs on my dad’s side of the family. An aunt and uncle passed away when young from complications of end-stage renal disease. Little did I know that my healthy lifestyle will hopefully give my mom another chance to live with a healthy new kidney.

My mom never asked me to be a donor. I just knew from the beginning that, if given a chance, I would donate my kidney to her. I am a registered nurse and I work in clinical research for a biotech company in Alameda. I used to work in long term care, emergency medicine, and oncology. I’ve cared for patients affected by kidney disease, and I’ve seen how the disease affects



their quality of life. My mom is not on dialysis yet and we hope to get the transplant done before she gets to that point.

The BAAKP support group has been a source of courage for my mom and me. Since we joined the BAAKP support group, our worries and fears have changed to hope, empowerment, and resilience.

Editor’s Note: Since Toni agreed to write this article, she has joined the BAAKP Board of Directors. We are so pleased to have her be a part of the board.

Thank you to our Community Partners

The Bay Area Association of Kidney Patients (BAAKP) is so appreciative of our Community Partners who have been generous with their donations in 2020-2021. Special thanks go to:

Alta Bates—Summit; Palo Alto Medical Foundation; and California Pacific Medical Center for the use of their facilities. Although we ceased meeting in person in March 2020 due to COVID, these institutions allowed us to meet at their facilities in 2019-2020 for our support groups and educational presentations.

Satellite Healthcare sponsored our monthly support groups and the video recordings of our in-person educational presentations. They also presented a very generous donation for our 2020 fundraising campaign.

A grant to help with BAAKP operational costs came from the University of California San Francisco Department of Nephrology research group headed by Anoop Sheshadri, M.D., Assistant Professor, Nephrology.

With the support of these Community Partners and the tremendous contributions from our members, BAAKP will be able to continue our support for our over 1200+ members.

I've Got Your Back

It was a long road together until Rudy passed away in April 2020. Years ago, Rudy was diagnosed with diabetes. Both his father and sister had diabetes as well, and both had passed away with kidney failure; only one sister remained. Rudy and Virdie Reed (his husband) lived in San Jose when Rudy was diagnosed with End-Stage Renal Failure. He began peritoneal dialysis (PD) in February 2010 at Satellite Wellbound in Milpitas. Immediately after starting dialysis, his symptoms of fatigue, lethargy, and intestinal upsets subsided.

Rudy and Virdie soon realized what a huge mental undertaking dialysis was and attempted to leverage the services through Wellbound. Unfortunately, it became difficult to establish rapport with the frequent staff changes there. They felt they needed more.

In 2015, Virdie had an aunt who had a friend (Phil Wyche) who introduced them to the BAAKP support group. Immediately, they felt at home with others who were dealing with diabetes and kidney failure. Things then stabilized, and they realized that they could travel while Rudy was on peritoneal dialysis.

They traveled to Texas to visit Rudy's family, then bravely took three different cruises, including one to Alaska. The materials needed for PD were delivered to the land-based hotels at each of the cruises' departure points. They visited Germany to see Virdie's side of the family, where the dialysate was delivered to Virdie's grandmother's house! In all, they took at least 15 trips! Virdie & Rudy were grateful they could take all of those trips!

In early 2017, Rudy came down with pneumonia, was hospitalized twice, and then developed peritonitis. Because of the peritonitis, he needed a temporary hemodialysis (HD) catheter in his shoulder. He had done seven years of PD before HD - quite a feat! Rudy applied to be on the kidney transplant list, and amazingly, Virdie was a match! They took a trip to Hawaii in September 2019, and then a week after their return Rudy had open heart triple bypass surgery.

As his caregiver, Virdie did what was necessary to navigate the world of dialysis and transplant, as Rudy found the "red tape" impossible. Virdie agreed he "had his back," and they went through it together. Due to a heart attack, Rudy passed away on the evening of April 26, 2020, after spending a wonderful day in San Francisco. Virdie wants to continue volunteering with BAAKP, using his photographic experience.



Rudy (left) and Virdie Reed

Kidney Humor



...and this dish is totally potassium-free!

Cartoon by Peter Quaife from the *Lighter Side of Dialysis*, Vol. 1

Post Office Box 2332
Menlo Park, CA 94026-2332

Phone: (650) 323-2225
Email: info@baakp.org

Educating & Supporting Kidney Patients!

Please visit our website at

www.baakp.org

to make a donation, read back issues
of our newsletters, and view videos of
our past meetings. Your help is
greatly appreciated!



Medicare in 2021: A BAAKP Webinar

The BAAKP is excited to announce that we will be hosting our first webinar in April! Our speaker will be **Marcelo Espiritu**, Health Insurance Counseling & Advocacy Program (HICAP) Director at Sourcewise in Santa Clara. HICAP's Medicare in 2021 presentation will inform you on important Medicare changes that took effect in 2021 and will also discuss Medicare as it relates to kidney patients.

HICAP provides free and objective Medicare counseling to Medicare beneficiaries, their families and caregivers to understand their Medicare benefits and best healthcare options.



Medicare alone can be overwhelming. HICAP counselors do not sell, endorse or are not affiliated with any insurance companies. Their goal is to inform and educate the community so you can make an informed decision on something as important as Medicare. Please join this California-certified HICAP counselor for an objective and unbiased Medicare presentation.

There will be an opportunity for you to submit questions.

Mark your calendars and please join us **Sunday, April 11, 2021 from 1-2 pm** for this FREE webinar. Register at baakp.org.

