



## The Renal Warrior: A Second Chance To Live

Two weeks after being diagnosed with end-stage renal disease, **Wilson Du (also known as the Renal Warrior)** found himself on the floor of his kitchen, unable to move from the pain of his body swelling up with 60 pounds of fluid. Due to stubbornness in accepting his diagnosis, he had avoided getting his fistula placed to begin receiving dialysis. This action caused him to stay in the hospital for six weeks; there, he would finally start dialysis. After six weeks with limited movement, his muscles began to atrophy. After his dialysis treatment, he would have the option to be brought to a chair or his bed. Wilson recalled, "Feeling completely broken – mentally, physically and spiritually."

At diagnosis, Wilson weighed 315 pounds. To qualify to be on the transplant list, **he would have to lose 100 pounds.** "Just a few weeks ago, I was out with my friends, my coworkers, living my life. Just a few weeks ago, my career was skyrocketing. Just a few weeks ago, I had so many hopes and dreams. And now, all of a sudden, **I only had one mission: to live.**" At last, Wilson chose to fight: to qualify for the transplant list and his continued survival.

He started small (walking to the front door was the first step), and every day he would challenge himself to go farther – whether he was using a cane or crutches, it wouldn't matter. The only thing that mattered was the mission to survive.



Within a year, Wilson had managed to accomplish more than survival; he was running 5k's and half marathons. He had begun biking (including a ride of 70 miles from Ontario, California to Palm Springs in January 2018), and through diet and exercise had managed to drop from 315 pounds to 220. In addition to qualifying

for the transplant list, he was also sharing his story with others to inspire them to fight as he did and to bring awareness to a disease with little information out there. "One of the scariest things was not knowing anything about kidney disease... a Google search places the average lifespan of a dialysis patient at 5-7 years. While post-transplant patients were running 5ks and half marathons, the same could not be said of dialysis patients."

After completing the bike ride from Ontario to Palm Springs was the announcement of a new mission — a bike ride from

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

Edited by Ryan Madison

# Understanding Your Lab Results

At the 2019 Fall Educational Presentation, BAAKP had the privilege of hosting **Mitra Sorooshian, MD**, who spoke about our lab results and what these results mean for kidney patients. Dr. Sorooshian is a nephrologist at Palo Alto Medical Foundation in Mt. View and Medical Director at the Satellite Dialysis Unit in Sunnyvale.

**Dr. Sorooshian** began by stating that 15% of the adult population in the US (approximately 30 million) have Chronic Kidney Disease (CKD), and 48% of that population are unaware of their condition. CKD is more likely to occur in men than it is for women, and non-white ethnic groups are more likely to have CKD than Caucasians. Dr. Sorooshian noted that the incidence of CKD has gone up dramatically over the last 30 to 40 years, but the number of transplants has not increased significantly.



And while genetics can sometimes play a role, these other conditions can lead to kidney disease:

- Diabetes
- Hypertension/Cardiovascular disease
- Autoimmune disease
- Kidney stones or infections
- Cancer
- Family history of kidney disease
- Older age
- Chronic NSAID use (Advil, Aleve, etc.)

The main function of the kidney is to filter the blood of excess water, toxins, and metabolites, creating the byproduct urine. The kidney is also responsible for the secretion and regulation of hormones such as renin (which regulates blood pressure), erythropoietin (which stimulates red blood cell production in bone marrow), and the activation of vitamin D3 (which is essential for bone, calcium and phosphorus metabolism). The main tests for kidney function are blood and urine tests:

**Serum Creatinine** estimates kidney function. Creatinine is a byproduct of muscle breakdown and metabolism. This number rises if kidney function is declining.

The **Glomerular Filtration Rate (GFR)** estimates kidney function and the stage of progression for kidney disease. Estimated eGFR is determined by age, gender, and body size and usually declines with age.

## Normal eGFR

Age	Average eGFR
0-29	116
0-39	107
0-49	99
50-59	93
60-69	85
70+	75

Dr. Sorooshian discussed when to start dialysis. Starting dialysis depends not only on GFR, but on other

## Normal Range for serum

creatinine (mg = milligrams / deciliter)

**Men: 0.8-1.3 mg/dL**

**Women: 0.6-1.0 mg/dL**

factors such as how the patient feels, their potassium levels, and their fluid status. The majority of patients begin dialysis at an eGFR of 10.

The **BUN (Blood Urea Nitrogen)** test measures the amount of nitrogen in the blood and urine. For the average person without CKD, the value should be 6 to 25 milligrams per deciliter. However, this number can be affected by forces outside of kidney function. An increase in BUN could mean dehydration, a high protein diet, or bleeding; a decrease in BUN could indicate malnutrition, a low protein diet, or liver disease. As Dr. Sorooshian pointed out in her presentation, the most common reason is dehydration. So, drink your water!

Another blood test registers the levels of **Potassium** in the body; healthy kidneys remove potassium from your blood. The normal ranges for potassium are 3.5 to 5.0 Eq/L. Impaired potassium excretion by kidneys can lead to a condition called hyperkalemia, which can cause muscle weakness, paralysis, cardiac arrhythmias, and even sudden death.

The test for **Serum Bicarbonate** measures the acidity of the blood. The average pH level in the human body should be between 24-31 mEq/Liter. With kidney disease, this number may be lower due to the inadequate removal of acid from the blood. The goal for kidney patients is to keep this number above 21 mEq/L.

**Calcium and phosphorus** levels within the blood are vital as they affect the health of bones, the vascular system, and the production of blood cells. Patients with CKD can accumulate calcium and phosphorus in their blood, leading to several bone disorders.

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## Understanding Your Lab Results (Continued from Page 2)

**Phosphorus** levels can be controlled by maintaining a low phosphorus diet by avoiding dairy, nuts, legumes, chocolate, dark colored soda, and processed meat. High phosphorus levels can lead to conditions like renal osteodystrophy, causing bone loss, bone pain, and fractures. Calciphylaxis is usually seen in end-stage renal disease and is the calcification of small blood vessels.

The final blood test measures **Hemoglobin**, found in red blood cells that carry oxygen throughout the body. Anemia is common in CKD patients because diseased kidneys release decreased erythropoietin hormone to the bone marrow, which is needed for red blood cell production. Normal hemoglobin levels for men are higher than 13.5g/dL and, in women, more than 12.0 g/dL. The treatment goal using erythropoietin replacement is 10-11g/dL.

**Proteinuria** is any amount of protein in the urine (it presents as foam or bubbles in urine). Microalbuminu-

ria is a condition with the smallest amounts of protein in urine and indicates a high risk for diabetic nephropathy. Microalbuminuria can be reversed with low sodium and low protein diet, blood pressure control, blood glucose control, and discontinuation of ACE inhibitor and ARB blood pressure medications.

*Thank you,  
Dr. Sorooshian,  
for your talk!*



Dr. Sorooshian can be reached at 650-934-7400 at the Palo Alto Medical Foundation. To view Dr. Sorooshian's complete presentation, go to [https://www.youtube.com/watch?v=S\\_4SL9PB6II&t=626s](https://www.youtube.com/watch?v=S_4SL9PB6II&t=626s)

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

## You Did It! Another SuperKidney Effort!



Thanks to the exceptional number of individuals who donated to the 2019 year-end fundraising, the Bay Area Association of Kidney Patients (BAAKP) **raised \$13,811.00**. We much appreciate the efforts of our donors and BAAKP Board Members. And with a matching donation from a generous member, the total reached

**\$18,811.00**. The BAAKP is grateful for the

help of these individual donors, and looks forward to a great 2020! 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, these monies do not cover our entire total

yearly budget of about \$27,000. Our budget was augmented by institutional grants received in 2019. These grants were provided by Satellite Healthcare, Palo Alto Foundation Medical Group Community Health Care Endowment Fund, and NxStage Medical.

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



## We Thank You All For Your Generosity!



## The Renal Warrior: A Second Chance To Live (Continued from page 1)

Sacramento to San Diego before the end of the year. This bike ride of 450 miles took 15 days to complete with six different dialysis locations along the way. Since then, Wilson Du has been working on a documentary to capture his journey as a dialysis patient completing the 450-mile bike ride. He hopes the documentary brings awareness to the public about kidney disease and shows those with chronic kidney disease that there is hope to overcome the disease's obstacles. Additionally, he has started a gym in Alameda, California, called **Mission HQ**. This gym is his way of sharing with others who are struggling to start their first steps towards their goal of surviving. The primary mission of the Mission HQ is to provide a judgment-free place where the chronically ill, elderly, and



those who need it the most can come to transform or get better free of charge.

The BAAKP thanks Wilson Du (aka the Renal Warrior) for sharing his kidney story at our educational presentation and for all he is doing to inspire and help kidney patients.

Find out more information about Mission HQ at [themissionhq.org](http://themissionhq.org).

To watch Wilson's talk in its entirety on YouTube, go to <https://www.youtube.com/watch?v=ExVJHlRV-cM&t=21s>

You can also follow Wilson on:



Facebook page @TheMissionHQ



Instagram @RenalWarrior2016



YouTube: Renal Warrior

## Support Group Meetings

Due to Covid-19, all in-person BAAKP events (Education Presentations and Support Groups) were postponed starting in March until further notice. But don't worry! We started having our monthly support group meetings online via Zoom! We meet on the 2nd Sunday of the month from 1-3 pm. You can register online at <http://www.baakp.org/calendar.html> to attend the meetings.

### *Upcoming Zoom meetings are:*

- August 9, 2020
- September 13, 2020
- October 11, 2020
- November 8, 2020
- December 13, 2020



# Risks of Skin Cancer After Transplant

**Sarah Arron, MD, PhD**, Dermatologic Surgeon and Director of the High-Risk Skin Cancer Program at University of California San Francisco Medical Center, spoke at our September 2019 Educational Presentation about the increased risk of skin cancer in transplant patients. The required immunosuppressants after transplants increase not only the chance of being affected by skin cancer but also the mortality rate from skin cancers.

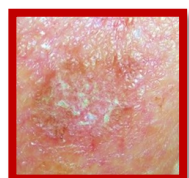
**The good news is, skin cancer is preventable!** Since summer is here, it is the perfect time to start a new routine to protect yourself from cancer-causing rays. The best choice for skin protection is sunscreen with an SPF listing of 30 and over, as well as being listed as a broad-spectrum. Broad-spectrum sunscreen protects from both harmful UVA and UVB rays. To take full advantage of the protection provided by sunscreen, you have to apply it liberally, 1-2 ounces (about one shot glass) for the exposed area. For it to bind to your skin, it should be applied about 30 minutes before sun exposure and every 1-2 hours after that point with continuous sun exposure. Only about 40% of transplant patients reported using sunscreen regularly, increasing their vulnerability to, and chances of skin cancer.



There are three main types of skin cancer: the most common non-melanoma type of cancer in the United States is **Basal Cell Carcinoma**. This cancer rarely spreads throughout the body and appears as a pink, waxy bump. This type of cancer can be protected against with the use

of sunscreen and limited exposure to the Sun. By being a transplant patient, you are **ten times** more likely to contract this form of skin cancer.

Next is **Squamous cell carcinoma**. As a transplant patient, you are 65 times more likely to contract this type of cancer, and it is the most common type of skin cancer in pediatric and adult transplant patients. This skin cancer looks like large red bumps and can present as scaly-rough patches of skin. This type of cancer multiplies and is especially aggressive in transplant patients.



The third type is **Melanoma**; this is a skin cancer with dark coloration, and is asymmetrical, raised, and changes shape over time. Only 4% of diagnosed skin cancers are melanomas, but they cause 77% of skin cancer-related deaths.



Use the ABCDE method to identify possible melanomas:

- A — Asymmetry of shape
- B — Irregular border
- C — Variation of color
- D — Diameter more than 6 millimeters
- E — Evolving (changing)

Skin cancer self-screening is recommended by dermatologists between appointments. Check your face, ears, neck, chest, and belly. Women will need to lift their breasts to check the skin underneath. Check both sides of your arms, the tops and palms of your hands, and your fingernails. Sitting down, first check one leg, then the other. Inspect the bottoms of your feet, calves, and the backs of thighs. Use a hand mirror to also inspect the back of your neck, shoulders, and upper arms, buttocks, and legs.

Early detection is important in treating skin cancer; your dermatologist can help determine your level of risk for skin cancer and can help you determine how often to have them examine your skin, as well as show you how to do the self-check. The UCSF Transplant Skin Cancer Network has an ongoing study in which they need the help of transplant patients. If interested, you can learn more at their website: <https://skincancer.ucsf.edu/>.

## Risk factors for skin cancer after transplant

- Older, white male
- Caucasian/white, especially with blue or green eyes
- Blond or red hair
- Burn easily in the sun
- Had skin cancer before being transplanted
- Heart and/or lung transplant
- Increases with more years on immunosuppression
- History of warts

## Transplant drugs that can increase the risk of skin cancer

- Cyclosporin, Azathioprine — **Highest Risk**
- Tacrolimus, Cellcept, Mycophenolate — **Middle Risk**
- Sirolimus (rapamycin) — **Lowest Risk**

View a video of this entire Educational Presentation at <http://www.baakp.org/new-videos.html>

*We extend our thanks to Dr. Arron for taking the time to educate our members about skin cancer risks after transplant. To contact Dr. Arron and her staff, phone 415-353-7878.*

*We also thank the sponsors of this Educational Presentation, Medeor Therapeutics.*

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# Transplants without Immunosuppression: Medical Trials

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**Stanford Transplant Nephrologist, John Scandling, MD** joined our Fall 2018 Educational Presenta-



tion to describe research focusing on transplants without transplant medications. Dr. Scandling is Medical Director of Stanford Adult Kidney and Pancreas Transplantation and is a principal investigator in these long-term studies.

Dr. Scandling began by explaining the meaning of **tolerance**:

“the specific absence of a destructive immune response to a transplanted tissue without immunosuppression.”

**The goal of the Stanford studies** is to avoid rejection of the transplanted organ and also from complications due to immunosuppressive medications such as infections, cancers, kidney damage, diabetes, high blood pressure, and excessively high lipids. And by removing all potentially harmful transplant drugs, both the life of the patient and transplanted organ can be extended.

Dr. Scandling commented that you could live on dialysis, but a transplant offers a better lifestyle. “Only one in 5 patients on dialysis have listed themselves for transplant,” he remarked. The ultimate goal is **“one transplant kidney for life!”**

To create tolerance in the recipient, **“Chimerism”** should exist. That is, foreign (donor) blood cells will coexist in the recipient with the recipient’s native cells. This “mixed chimeric immune system” will recognize the transplant as not foreign. Rejection of the donor’s kidney should not occur, despite the lack of immunosuppressive drugs.

Six weeks or more before the surgeries, the **living donor** is prepared with medication to stimulate the release of blood stem cells from his bone marrow into

his bloodstream, then leukapheresis (a procedure similar to dialysis) removes the blood stem cells from the donor’s circulation.

Theoretically starting on Monday, the day of the transplant, the kidney recipient receives Anti-thymocyte globulin (ATG) for 5 days. He also begins taking standard doses of immunosuppressive medications. On Tuesday, the patient has total lymphoid irradiation (TLI), an essential part of the recipient’s “conditioning regime.” To encourage the patient’s bone marrow to accept the donor’s cells, the patient receives TLI of his lymph nodes, spleen, and thymus, while shielding other vital body parts. The dose of radiation is much smaller (25%) than that used to treat cancer and is a safe and effective procedure.

On Friday of the first week, the patient leaves the hospital for the weekend and then returns on Monday for further outpatient treatment. He receives daily TLI, plus an infusion on day 12 with the kidney donor’s stem cells and T cells. If all goes well, and there is no sign of rejection of the kidney, the doctors will gradually reduce the immunosuppressive medications over months. The researchers are looking at the patient’s blood for a mixed chimerism of both donor’s and patient’s cells over the long term.

## **Human Leukocyte Antigens (HLA) matching.**

There are 6 antigens of importance to kidney transplantation. You receive 6 HLA antigens: 3 from your mother, 3 from your father.

Currently, there are two living donor clinical trials at Stanford. The first trial, begun in 2005, involves **HLA-identical siblings**. The second trial consists of **HLA Mis-matched siblings**. The first trial will directly benefit only a few kidney patients, because of the difficulty of finding a donor sibling with all 6 HLA antigens to match the recipient. The odds of finding a donor sibling with just 3 of the HLA antigens matching is much higher and will ultimately be of more benefit to a larger group of kidney patients.

The results of the two trials so far have been very encouraging. The early stage of the HLA-Mismatched trial was in the years 2000-03; two patients who came off the immunosuppressive drugs had to return to them after developing acute rejection (they are both doing well today).



In both sets of patients, there's been no Graft vs Host Disease (GVHD) and no added risk to the transplanted kidney. Citing a 2015 publication of this research, 22 patients were in the HLA Matched group. Chimerism remained in 21 of them for anywhere from 2 to 42 months, and the majority are no longer taking transplant immunosuppressants! Early benefits were less high blood pressure, less elevated lipids, and no diabetes. In the early stages of the next research project with HLA Mismatched patients, 2 out of the 6 test patients retained mixed chimerism for an average of 2.5 months, with an average of 4.5 months without immunosuppressant medications! The second stage of the HLA-mismatched trial began in 2010 and the achievement of durable mixed chimerism, the key to tolerance, is its goal.



Stanford is currently enrolling patients for these two Clinical Trials. Contact Ashi Shori, the Study Coordinator at 650-736-0245 or [ashas@stanford.edu](mailto:ashas@stanford.edu).

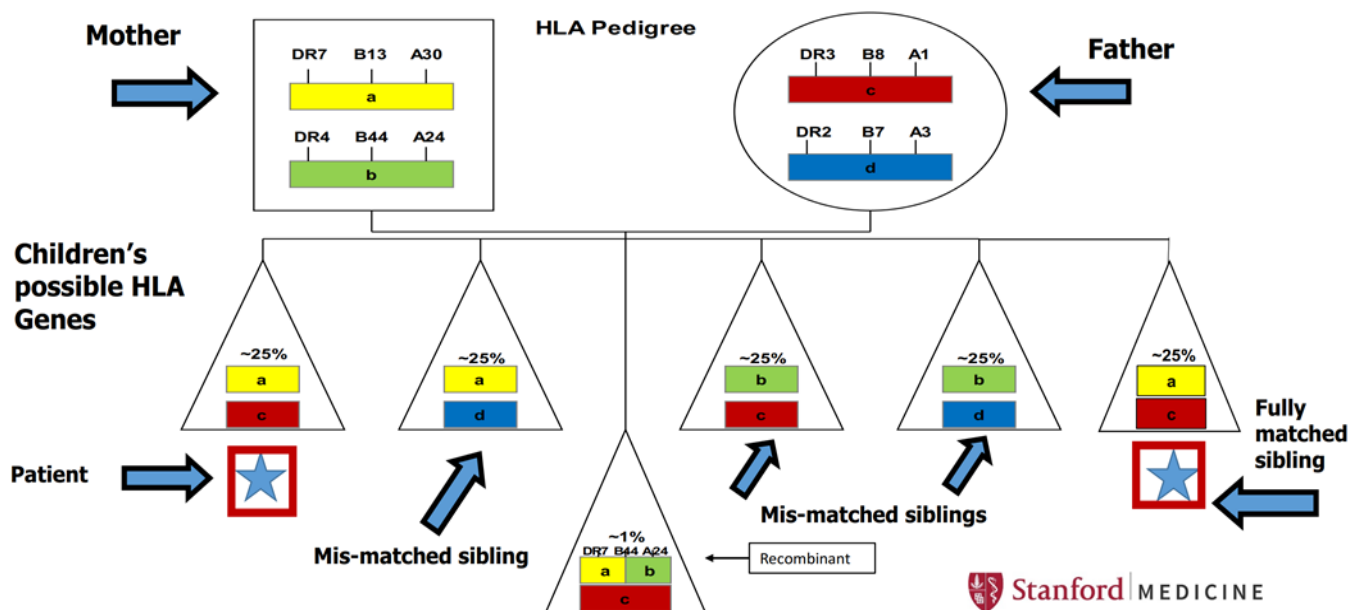
Here are the **Eligibility Requirements** for the HLA-Mismatched Trial:

- Reside within a two-hour drive or two-hour flight to Stanford;
- Age less than 60 years at the time of transplant;
- Not have a kidney disease at high risk of recurrence after transplant;
- First transplant;
- Same blood type as the donor;
- Two HLA match (one DR match) with the donor
- No donor-specific antibody;
- Panel reactive antibody (PRA) less than 80%;
- Epstein-Barr virus antibody positive unless the donor is EBV antibody negative; and
- Medical insurance that will cover transplantation at Stanford.

We thank Dr. Scandling and Dr. Steven Busque for taking their Sunday afternoon to educate and support Bay Area Kidney Patients. We also are grateful to Medeor Therapeutics for their sponsorship of this Educational Presentation.

The complete video presentation is available on the BAAKP website at <http://www.baakp.org/video-archive-1.html>. Thanks to Satellite Healthcare for their sponsorship of our videos.

### HLA Genes are Linked Together to Form Haplotypes



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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!



## **BAAKP Podcast Debut!**

The BAAKP was honored to be asked by Satellite Healthcare to be a part of their NephTalk Magazine by recording a podcast discussing the value of support groups. Satellite Healthcare hosts a monthly podcast series where they discuss topics of interest to nephrologists and the kidney community that highlight patient stories, industry advancements and nephrologist best practices.

Phil Wyche (President and Support Group Leader) and Debra Elmore (Executive Director) of BAAKP recorded the podcast with Christopher Springmann in February 2020. In the podcast, they discuss how the BAAKP helped them on their personal kidney journeys and how support groups can help all kidney patients.

Among the subjects discussed were how the BAAKP support groups are used to promote self-awareness and self-preservation. In particular, Phil talked about the importance of including your family – not just bringing them to support group meetings but including them in what is going on with you (your emotions, symptoms, and diagnosis). Kidney disease can be very frightening, and it is best not to try and go it alone.

Debra stressed that it is best to join a support group as soon as you find out you have kidney disease. At a support group you can learn how to make yourself healthier and try to preserve your kidney function for as long as possible. You can also learn about different dialysis modalities and how to best prepare for a transplant.

Everyone's story is unique but there are also similarities. It helps people to come to a support group and realize "someone else has done this" or "someone else has gone through that." It always helps to know that you are not alone.



You can listen to our podcast and others on the Satellite Healthcare NephTalk website at <https://www.nephtalk.org/nephtalk-magazine/2020/june/seeking-a-support-group-listen-and-act/>

We appreciate Satellite Healthcare sponsoring our support groups and for giving us a chance to reach even more patients with the podcast.