

Kidney Konnections

A publication of the



Bay Area Association of
Kidney Patients

Educating & Supporting Kidney Patients

The Bay Area Association of Kidney Patients is an all-volunteer, non-profit, 501(c)3 organization formed to educate and support Bay Area kidney patients. Attend our Educational Presentations, Support Group Meetings, read the *Kidney Konnections* newsletter and our interactive social website

www.baakp.org

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650-323-2225

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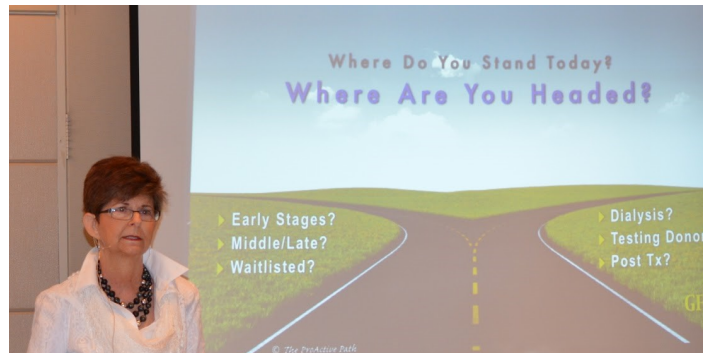
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Successful Strategies for Hopeful Transplant Recipient by Kim MacBeth

On May 17, 2015, the BAAKP held its 26th Educational Presentation, the second event of the *Charles & Joan Hornsgren Kidney Education Series*. Risa Simon, our special guest speaker, discussed *Successful Strategies for Hopeful Transplant Recipients*. Ms. Simon is the CEO of TransplantFirst Academy, a Kidney Patient Advocacy Coach, and author of *Shift Your Fate: Life-Changing Wisdom for Proactive Kidney Patients*. She is also a happy transplant recipient, having received a Preemptive Living Donor Transplant in 2010. (Preemptive Transplant means she received her transplant prior to the need for dialysis.)



Ms. Simon began her presentation by first applauding the audience for continuing their kidney education and then applauded her recently transplanted kidney named "MAK, Melissa's Amazing Kidney." She finally celebrated Melissa

by giving her a kidney and changing her life, allowing Risa to optimize the rest of her years. Risa stressed the importance of being prepared and quoted author Elmore Letterman saying, "Luck is what happens when preparation meets opportunity." She then asked the attendees, "Where do you stand today? Where are you headed?" A poll of the audience revealed how many were waitlisted for a transplant and how long they had been on the "list". Many have been waiting several years, and one person shared that he had been waiting 7 1/2 years.

Next, she defined both Glomerular Filtration Rate (GFR), a measurement of the percent of kidney function and End Stage Renal Disease (ESRD), which occurs when the GFR declines to less than 15. She emphasized the need to be your own advocate and to partner with your healthcare providers, especially as you approach Stage 4, a GFR of 15 to 29. "The best thing you can do right now is to visualize your future today; don't wait until sickness triggers action," was her advice. Risa said, "There are options available other than dialysis and waiting on the transplant list, in some cases a very

End Stage Renal Disease Tiers

STAGE	eGFR
1	>90
2	60 - 89
3	30 - 59
4	15 - 29
5	<15

(Continued on page 2)

long time, for a kidney.” There are actions you can take, but it’s going to take everything you’ve got. You will need to change your thinking to be “willing to do whatever it takes to live your best life possible.” Risa said, “**The main goal is to optimize your choices, and the key objective is to trigger your best options while they still count.**” She encouraged attendees to become a truth seeker by first understanding the differences between Dialysis and Transplant.

According to the United States Renal Data Service (USRDS), transplantation offers a longer life expectancy. The patient benefits even more from a “preemptive” transplant: which affords the best outcome. There’s less depression, more energy, lowered chance of rejection, improved graft function, a greater chance to retain employment, and an all-around better quality of life.

DIALYSIS <small>Can Be Referred To As A Bridge or Holding System</small>	TRANSPLANT
10 -13 % FUNCTION	>60 % FUNCTION
Time Demands/Diet Restrictions	‘Untethered’ Quality of Life
Exhaustion, Infection, Anemia & Heart Disease	Immunosuppression Drugs S, Increased Risk For Cancer & Infections
Increased Mortality Rates	Better Survival Rates

Risa then shared the kidney patients “Call to Action.” She encouraged everyone to follow these important steps:

- **Step 1:** Make the commitment to be proactive, not reactive.
- **Step 2:** Let your voice be heard, learn to become your own best advocate.
- **Step 3a:** Insist on early transplant evaluation. Request an early evaluation (Stage 4 at about 25 GFR).
- **Step 3b:** Explore transplant center options. Visit nearby centers, but don’t exclude those at a distance.
(Editor’s Note: This will require a referral from your nephrologist, and you may have to insist on that!)
- **Step 3c:** Start contemplating potential donors.
- **Step 4:** Start sharing your story.
- **Step 5:** Educate others on

the value of living donors.

- **Step 6:** Enlist volunteers.
- **Step 7:** Find a mentor – go to the websites of the [American Association of Kidney Patients \(AAKP\)](#), [National Kidney Foundation \(NKF\)](#), [American Transplant Foundation \(ATF\)](#), [The Proactive Path](#). And of course, do contact the [Bay Area Association of Kidney Patients \(BAAKP\)](#) for help, and attend their group meetings.
- **Step 8:** Expand your circle of influence – by using email blasts, bulletin boards and social media outreach.
- **Step 9:** Commit to continuous learning.

Risa said that most people don’t know about a Living Kidney Donation (LKD); and that 12 people die every day while waiting for a deceased donor. There are over 100,000 people waiting for a kidney, and the average wait is five years. Deceased donation is not enough as there are only about 5,000 consented and qualified deceased donors per year.

However, a living donor has other advantages. Receiving a kidney from a living donor will remove at least one kidney patient from the deceased donor wait list. Living donors are expected to live a full life with just one kidney. Most people don’t realize that the donor does not have to be related to the recipient or that the blood type isn’t a deterrent with paired donation.

Ms. Simon showed the very emotional video clip *Chain of Hope: Patients of a six-way kidney swap meet for the first time*. It highlighted patient Mark Kim <http://www.cbsnews.com/videos/patients-of-six-way-kidney-swap-meet-for-the-first-time/>. Mark was on dialysis for two years; his sister had offered to donate her kidney, but wasn’t his blood type. The paired donation program made it possible for Mark to receive a kidney from someone else who offered a better match, after his sister agreed to join the paired program with her brother and donate a kidney to a blood type matched person in the same chain. Mark named his kidney “Corporal” to honor his donor Corporal Liz Torres.

Ms. Simon encouraged the attendees to AVOID the following Patient Challenges:

Neglecting to take full ownership of your health.

Be more accountable: know your lab values; monitor your blood pressure; keep a symptom diary, and understand your medications. Ms.

Simon provided blank forms for the attendees to maintain these records.

Neglecting to steer your appointments. Attend your doctors' appointments with a list of questions and then take notes.

Using wishful thinking or denial as a coping mechanism.

Resting on your laurels.

Expecting everything you need to know to come from your doctor or medical personnel.

Risa said, "It's not a matter of if or when your kidneys will fail; it's a matter of failing to secure your best option while you still have a fighting chance." She warned the group that there may be misunderstandings, unexpected surprises, and heart-wrenching disappointments – but to not give up.

Risa then shared a video clip *Kindred Spirits Share Their Inspiring Kidney Donation Story* (<https://www.youtube.com/watch?v=PYg4LJOYZnE>), which details her journey with her donor Melissa Blevins, administrator for the Transplant Center and Living Donor Programs at Mayo Clinic's campus in Arizona. Melissa realized she needed to "walk the talk" and offered to donate one of her kidneys to Risa. As it turned out, they matched as close as sisters. The transplant occurred in 2010. Blevins said donating a kidney was the highlight of

he said "it was like someone turned the lights on." Phil said that he was, for years, in denial about his kidney disease and ended up on hemodialysis, later switching to peritoneal dialysis. He was unhappy and depressed on dialysis and had many delays because of other medical issues, but he became very proactive. After eight years on dialysis, he got "the call", and had his transplant in November 2013. Debra and Michelle, who are best friends, shared their story, with Michelle donating a kidney to Debra preemptively. Debra said the hardest part for her was accepting the donation from Michelle, and she is still in awe of that gift. Michelle shared that it was such an incredible opportunity and a gift to herself to be able to do this for someone that she loved so dearly. She said, "How many people get to do that?"

The BAAKP appreciates the enthusiastic and inspiring talk given by Ms. Risa Simon at this special event. Contact her at Risa@ShiftYourFate.com or at (480) 575-9353. Special thanks go also to Ms. Mary Horngren and her family for their support of the Charles and Joan Horngren Kidney Education Series. We also acknowledge the Palo Alto Medical Foundation for their continued assistance.



Left to Right : Michelle, Debra, Mark and Phil

her life. I "have watched the miracle of organ donation from a clinical and professional perspective for years," she said. "I knew the experience would be great, but I didn't know how great."

The Educational Presentation concluded with the ever-popular Patient Panel. Panel members were Mark Kim, Phil Wyche, Debra Elmore, and Michelle Chatorian. Mark was part of the previously mentioned "[transplant chain](#)" initiated by an altruistic donor. He shared that his experience with transplant versus his time on dialysis and

FREE **Save the Date!** **Refreshments**
Donor Sabbath

November 15, 2015



Movie Time!

Mid-Peninsula showing of the award winning movie

Perfect Strangers, the Movie

"tells the story of two unique and engaging characters. One is Ellie, who embarks on an unpredictable journey of twists and turns, determined to give away one of her kidneys and the other, 500 miles away, who endures daily home dialysis, waiting for that perfect kidney match.

12 noon to 3 pm Trinity Hall
330 Ravenswood Ave, Menlo Park 94025

On Donor Sabbath, we are remembering and thanking all who have donated their precious organs both in life and death. **Reserve your seat** for this heartwarming event at: www.baakp.org or call 650-323-2225

Looking to the future... Custom kidneys?

Another way to get a kidney transplant may be possible with a technique being investigated at Wake Forest Baptist Medical Center. Researchers there, headed by G. Orlando, MD, Ph.D., use kidneys that have been deemed unfit for transplantation and discarded. (Each year, Over 2600 donated kidneys are rejected for transplant.)

They wash the kidneys in a detergent to remove all the cells

from the structure. An analysis of the decellularized organs revealed that antigens likely to cause an immune



response were removed in the cleaning process. The idea is to replace these cells with a patient's own kidney stem cells, creating a custom-made kidney. The hope is that this "personal" kidney won't be rejected, and the patient could avoid taking transplant medications.

The smallest parts of the kidneys are structures called the glomerulus vessels, where the actual filtering of the body's contaminants occur. Researchers reported that the size, structure and function of the micro-vessels in the glomerulus were preserved after the cell removal process and that vital proteins known as growth factors that regulate cell growth and function were retained as well.

Then, as a test, the team seeded stem cells derived from amniotic fluid on to the kidney "skeleton," with the result that those cells grew and were functioning as expected. This experiment proves that "discarded human kidneys are a suitable platform" and that "they behave as an effective and viable biosystem."

The next step is for the group to identify the necessary "kidney" stem cells and test those on the kidney frame. The hope is that these previously

discarded kidneys could be seeded with the patient's personal kidney stem cells to create a custom-made kidney, eliminating both the worry of rejection and the

At the End is My New Beginning A Kidney Disease First Person Story By Anna Mae Louie Olivares

I was diagnosed in 2007 with IgA Nephropathy, when a routine urinalysis showed I was excreting a large amount of protein and had microscopic hematuria (blood in my urine). I guess it was the beginning of my denying that eventually I may succumb to renal failure at a young age. My coping mechanism at that time was to make myself busy to divert my mind from thinking that I was not healthy. In fact, I didn't feel anything strange in my body. I failed to follow up with my Nephrologist because of the fear of any "bad news" during a doctor's visit. I was a resident physician, balancing a very stressful training in OB-GYN, doing 24-hour labor and delivery watch on every patient, and staying overtime in the hospital. How could I be so very neglectful of me?

I made myself believe divine intervention would heal my disease, and nothing harmful would happen along the way. I intentionally forgot about my own health and focused on taking care of others, until I started feeling fatigued and almost fainted during long hours of hospital duty. At that time, I had no idea my blood pressure was already over the top, and I had severe anemia. I went to the emergency department; but at the back of my mind, I knew that my disease had caught up with me. My blood pressure was 200/180; I was lucky I did not just drop dead that day while doing daily rounds on my patients. I was admitted to the hospital; and once again, I saw my nephrologist. At that time the Doctor's first question to me was, "Why?" Why did I not come and see her during all those years working in the hospital, with her clinic just around the corner? I had no answer. It's just that I was scared. I was frustrated, angry with myself, and depressed. For me,

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everything stopped right then. My plans and dreams all came to a halt.

But then, just when I thought my life was wasted, my husband's petition arrived for me to come and live with him in the U.S. I emigrated from the Philippines in 2012, knowing I had a better chance of treatment in America. When I arrived in the United States, my new Nephrologist immediately placed me on the transplant list. I was already in stage 5 renal disease, but I still refused dialysis. Much was going on in my life at that time; my beloved father was battling lung cancer, and I was away from my family. And, when the time came that I had to start hemodialysis, I had to be admitted to a hospital for the placement of my dialysis catheter. (Editor's Note: The best way to prepare for hemodialysis is to receive a **fistula** months before dialysis is necessary, instead of a catheter on an emergency basis.) My father passed away without me beside him because I also had to fight my own battle to be able to live. I was hit hard. I thought I could never recover. My heart and mind were broken, and I did not know how to bounce back to where I used to be. I was hard on myself because I was going through a lot of emotional and physical pain.



Anna Mae with husband Rey

Debbie Kurland, who encouraged me, saying I can still be who I want to be. Most of all, I was able to face those issues because of

Looking back, I would have not been strong enough to face all those issues within me had I not met my Nephrologist Dr. Shahrzad Zarghamee at Palo Alto Medical Foundation and a great team of dialysis staff at Satellite WellBound. My dialysis nurse Soraya Aghassi treated me not as a patient but like her own daughter. I had a great social worker

my loving and supportive husband whom I relied on for my strength when I was weak. Through all the ups and downs and struggles in my treatment, I became comfortable with doing dialysis. After doing in-center dialysis, my husband and I then trained for home hemodialysis.

Now I've shifted to peritoneal dialysis, giving me more flexibility in my treatment. After 3 years on dialysis, I've risen above my disease. There are still moments when I experience physical and emotional highs and lows, but I am now focused on winning my battle. I am on a new career path, I learned how to drive, and now I have passed the licensure exam to be a Medical Technologist. I'm starting to get my way around a new job at Kaiser Permanente in Redwood City. Since I have no kidney donor, it's still a long journey to a kidney transplant; yet I am looking forward to that moment when I get that important phone call! Until that day comes, my journey to a new beginning continues. □



For Those of Us Who Need to watch salt and potassium in our diets...

A national, well-known canned soup company manufactures two different versions of Cream of Chicken Soup. Let's compare some specifics of a single serving on the labels:

	Healthy Request	Regular
Fat	2.5 gm	8 gm
Sodium	410 mg	870 mg
Potassium	750 mg.	60 mg

Wow, when the salt ([sodium](#)) is reduced, **Potassium is added** for a total of **750 mg**, which is about one-third of the **daily 2000 mg allowance** for some kidney patients.

...We must become label-readers!



41ST NATIONAL PATIENT MEETING



NASHVILLE, TN | SEPTEMBER 25-27, 2015

American Association of Kidney Patients
National Kidney Patient Meeting*
September 25-27, 2015 *Nashville, Tennessee*

Topics covered include:

Innovations in treatment & care

*The importance of keeping patients
fully employed*

Healthy eating at all stages of kidney disease

National legislation and policy impacts on

living kidney donors and patients

Emergency preparedness for kidney patients

Social media & online tools in the Renal World

To Register:

Registration \$150 — Scholarships Available!

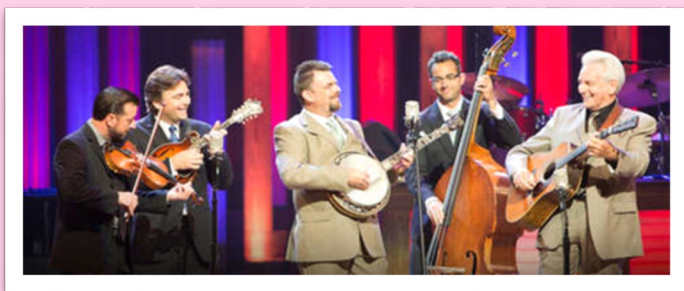
Go online to register at:

<http://www.aakp.org/community/programs-events>

or call: (800)-749-2257, Option 7, ext. 4.

Nashville Airport Marriott room reservations:

*Call (800) 228-9290 or (615) 889-9300 and reference
the AAKP meeting to receive the discounted rate of
\$145/night.*



*See you in "Music City" -
The Birthplace of
Country Music*

**The largest gathering of kidney patients, family and public policy experts in the U.S.*

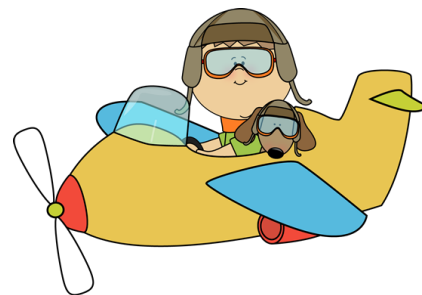
It's Vacation Season!!! How to travel while on dialysis!

Summertime and Holidays are popular times to travel. For dialysis patients, a lot of planning must come first. Here are some travel tips to help your trip go as smoothly as possible:

- ◆ Make plans at least 30 days in advance.
- ◆ Advise your Dialysis Staff of your plans to travel; also notify your nephrologist (kidney doctor).
- ◆ Ask the Dialysis Staff if the dialysis company has a center in the area you will be visiting.
- ◆ If you have a computer, you may find a dialysis center by going online, where you may search for a center by fields such as city, state or centers near the address where you will visit:
 - ⇒ <http://www.dialysisunits.com/index.php>
 - ⇒ <http://www.globaldialysis.com/search-for-dialysis-centres.html>
 - ⇒ www.dialysisfinder.com
- ◆ You may also call to make travel arrangements:
 - ⇒ Dialysis Finder (866) 889-6019
 - ⇒ FMC Patient Travel Services (866) 434-2597

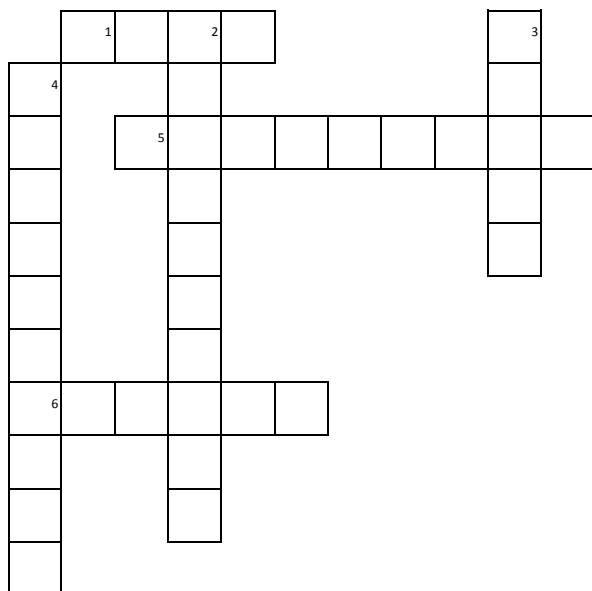
⇒ DaVita Guest Services (800) 400-8331

- ◆ Call the center you wish to visit to see if they are able to accommodate you as a visitor.
- ◆ Ask for a travel packet to be faxed to your home dialysis center.
- ◆ Be sure that all lab tests and other paperwork are sent to the center you plan to visit. Your Dialysis Center Staff can help.
- ◆ Make payment arrangements, if needed.



The most important thing to remember is you are not the only dialysis patient traveling. Chairs can fill up fast during the summer and holidays. Improve your chances of getting the treatment time you want at the dialysis center you choose...**plan ahead!**

What's Better Than Dialysis???



Across

1. Test to see if your blood _____ matches
5. Person who gets a kidney
6. Type of donor who, while alive, gives a kidney to someone

Down

2. Type of transplant received before going on dialysis
3. Person who gives a kidney
4. Surgery to get a kidney

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

Answers: 1. Type 2. Preemptive 3. Donor 4. Transplant 5. Recipient 6. Living



Bay Area Association of Kidney Patients

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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!

Educating & Supporting Kidney Patients!

SAVE THESE DATES !

Peninsula Events

Palo Alto Medical Foundation (3rd Floor)
795 El Camino Real, Palo Alto, CA 94301

Educational Presentation (1-4 pm)

- **January 31, 2016**

Support Group Meetings (1-3 pm)

- **August 9, 2015**
- **October 11, 2015**
- **January 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 20, 2015**

Support Group Meetings (1-3 pm)

- **July 12, 2015**
- **September 13, 2015**
- **November 8, 2015**

Board of Directors' Meetings
1st Tuesday of the month—6:00 pm
info@baakp.org (650) 323-2225

Help! I've just Learned I have Kidney Disease — What do I do Now?

On September 20, 2015, BAAKP will be in the East Bay for our Fall Educational Presentation. Our guest speakers will cover what every kidney patient needs to know about Chronic Kidney Disease. Nephrologist **Hussain Gilani, MD**, Chabot Nephrology Medical Group, will answer the questions of concern for newly diagnosed kidney



patients. Joining him to explain the basics of the kidney diet will be **Faith Tootell, MS, RD, CSR, FADA**, Renal Dietician and Nutrition Services Manager for Satellite Healthcare.

Please note: this event will take place at a new location.

We will be at the **Alta Bates Summit Hospital. Merritt Pavilion, 350 Hawthorne Ave, Oakland, CA 94609**. The meeting room is Fir 1&2, at the north end of the hospital adjacent to the Emergency Room. [Click here for a poster.](#)

Please join us on Sunday, September 20th from 1 to 4 pm for this **FREE** event. Refreshments and door prizes too!

Reserve your seat online at www.baakp.org/ or call 650-323-2225.

**SATELLITE
HEALTHCARE**
DIALYSIS • WELLBOUND