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Spring 2018



Bay Area Association of
Kidney Patients

Kidney Konnections

Taking Dialysis Home by Matt Reeder



We were very honored to have **Dr. Graham Abra**, Clinical Assistant Professor of Medicine, Stanford University;

Medical Director at Wellbound San Jose; and Director of Medical-Clinical Affairs at Satellite Healthcare be a speaker at our January 2018 Educational Presentation. Dr. Abra talked to our members about the better quality of life home dialysis gives kidney patients.

Fully **93%** of nephrologists would choose home dialysis over any other kind of dialysis treatment if they themselves needed dialysis! Only 2% of nephrologists would choose to have hemodialysis in a dialysis center.

Why would nephrologists so overwhelmingly prefer home dialysis if they needed dialysis themselves?

Once you are trained and able to perform dialysis at home, you have more flexibility in your schedule. This allows you to fit your dialysis schedule into your work, travel, and regular life. In contrast, in-center dialysis holds you to a set schedule at an outside

center which can be challenging. Dialysis treatment at home means relaxing at home rather than regularly and constantly traveling to a dialysis center.

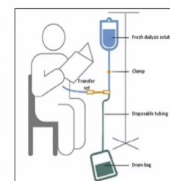
Also, when you control your own treatment, your loved ones can participate more directly and provide support to give you the best care possible.

Among the benefits offered by home dialysis are: fewer dietary restrictions than in-center hemodialysis (which is very rewarding to your overall quality of life); better sleep; healthier emotional well-being; and fewer drug prescriptions. Home dialysis allows you to enjoy very little to no recovery time. In contrast, patients who have in-center dialysis often need many hours after a dialysis session to feel good enough to get back to their life, while with home dialysis you feel good almost right away because of better treatment scheduling.

Home



Peritoneal Dialysis



Home Hemodialysis



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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

Taking Dialysis Home (continued from page 1)

Let's review some questions and answers that will help you get better acquainted with home dialysis.

What types of home dialysis are available?

There are two types of home dialysis available: Peritoneal Dialysis and Home Hemodialysis.

Peritoneal dialysis (PD) is the most common type of home dialysis. PD cleans your blood and removes extra fluids using one of your body's own natural filters, the peritoneal membrane. There are two types of PD: Continuous Ambulatory (CAPD) and Continuous Cycler (CCPD). Both are unique in that they are "bloodless." A surgeon places a tube called a catheter into your belly and dialysis is performed through the catheter. Equipment needed for dialysis (such as the bags of dialysis solution) is delivered to your home regularly.

With CAPD, you insert the dialysis solution into your belly (called an exchange) and it remains there for 4-6 hours. During this time, you can walk around freely. You normally perform 3-4 exchanges a day. The other type of peritoneal dialysis is where a machine called a cycler performs the exchanges for you and is usually done at night while you sleep.

There is also home hemodialysis (HHD) which is performed five or six times per week. Just like in-center dialysis, a surgeon places a fistula into your arm that is used to perform dialysis. Supplies and equipment are delivered to your home. During each treatment, you rest in a chair as you use your access point (fistula) and operate the dialysis machine, tubes, needle, and filter. You may also need to test your water or use special bleach or disinfectants for your equipment. This type of dialysis can be performed either during the day or at night.

Each home dialysis option presents some extra work including: training, picking up supplies at your clinic, managing your equipment and supplies at home, and still going to the clinic for your blood draws.

How long does training take?

Peritoneal dialysis training takes about two weeks and you will learn about infection control and how to perform the exchanges.

Home dialysis training takes about six weeks.

How much time does dialysis take each week?

To describe this, we have to include travel time, treatment time, managing supplies, clinic visits, and recovery time. In-center hemodialysis itself is almost a full-time job; while home dialysis treatments are more like a part-time job. Look at the hours needed:

	Dialysis treatment type	Hours
In-center	Hemodialysis	32
Home	Home hemodialysis	26
	Continuous ambulatory peritoneal dialysis (CAPD)	16
	Continuous cycler peritoneal dialysis (CCPD)	12

Do I need a home caretaker or partner to perform home dialysis?

It is always best to have a home partner to help, but many patients, after they receive sufficient training, can perform dialysis at home very safely. Your provider will supply you with a hotline for help (where you can reach a dialysis nurse on the phone 24 hours a day / 7 days a week).

What are the notable advantages and disadvantages of peritoneal dialysis?

ADVANTAGES – First, peritoneal dialysis (PD) preserves remaining kidney function better than hemodialysis, which is a large advantage to your long-term health. PD offers a more flexible lifestyle so you can maintain your independence. Next, PD allows you to use vascular access of a fistula later, after having utilized PD for as long as it is useful and healthy for you. Another great advantage is financial. Medicare will cover the costs of peritoneal and home hemodialysis training from the beginning, whereas Medicare coverage does not start for in-center hemodialysis until the third month of treatment.

DISADVANTAGES – PD patients have a risk of peritonitis and exit site infections which are very real and challenging problems. Drain pain can be a problem that can take some help and intervention.

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

Taking Dialysis Home (continued from page 2)

Catheter issues can arise but can be minimized by ensuring there is no constipation. Some cyclor brands/models can be challenging to manage due to alarms and user challenges. We recommend coming to our support groups to learn from other patients about the cyclor models they use and how it works for them.

We strongly encourage all of our members and friends who need dialysis to seek out home dialysis treatment if at all possible. The dialysis provider with the largest portion of its patients receiving home dialysis is Satellite Healthcare, as 20% of its 8,000 patients across six states receive their dialysis therapy regularly at home. We applaud this lifesaving therapy that provides a better quality of life for kidney patients and we were honored to have

Dr. Abra speak to our group. Contact Dr. Abra at AbraG@SatelliteHealth.com or 650-723-6961. Visit <https://homedialysis.org> for more information.



TRY AAKP (American Association of Kidney Patients)

Like BAAKP? Then you should try AAKP!

The AAKP Annual National Patient Meeting is the largest kidney patient education and advocacy meeting held in the United States. This three-day event provides patients and their care-partners the opportunity to gain information and advocacy skills they need to understand their condition and make informed choices regarding their care. Scholarships are available.

Click [here](#) to find more information about this great event, or call **800-749-AAKP** Toll-Free or email info@aakp.org. Hope to see you there!

43rd National Patient Meeting
June 8 - 10, 2018
St. Petersburg, Florida



When an individual chooses to become an organ donor (see donatelife.california.org), s/he is selflessly giving life to another person. Do you know how others honor that gift? At California Pacific Medical Center (CPMC) when a transplant surgeon and her coworkers stand around an organ recipient patient in a transplant surgery operating room, they take a moment of silence to honor the life of the donor, during which time a small tribute that was written by the donor's family is read aloud.

Dr Nikole Neidlinger, Organ Transplant Surgeon, and Chief Medical Officer at Donor Network West joined us at our January 2018 Educational Presentation in Oakland to share how she honors the life of every organ donor in her lifesaving surgical work. She and her colleagues at Donor Network West respect the life of every organ donor, while serving organ recipients and sharing tribute to families of the deceased donor. It is an incredible labor of love that Dr Neidlinger performs tirelessly.



Since 2003, the number of patients waiting for an organ transplant rises higher every year, while the number of patients receiving a transplant each year has stayed about the same.

The donor network that serves the Bay Area has the largest wait list in the nation. Blood type O has the longest wait of all due to the large number of O-type patients on the kidney transplant wait list. Right now, the wait time for a kidney in the Bay Area is about 7-8 years, which is a difficult trial for many while their health declines or they try to maintain their health while on dialysis.

LIVING DONORS:

A living donor kidney presents many benefits to transplant patients that cannot generally be achieved any other way. These benefits include:

- Shorter hospital stays for the transplant procedure

- Being able to plan the transplant operation for a convenient time
- A better chance to prepare the donor kidney for a procedure called "desensitization" which decreases the chance of organ rejection complications
- Increased probability that the donor kidney will last longer (15 to 20 years)
- The possibility of getting a new kidney before you go start dialysis, preventing some health risks.

Kidneys from a deceased donor will probably not last as long (an average of 10 years). In addition, while you are waiting for a deceased donor kidney, the call for the surgery can come at any time; therefore, the doctor's ability to make the best preparations for the best possible outcome is limited by time constraints.

A person who gives away one of his/her kidneys will likely benefit from the emotional feeling of giving life to the recipient. In addition, if the donor can give her organ to a kidney patient that she has to care for, her care burden is reduced after a successful transplant.

But there are some risks to being a donor. A living donor has a 1 in 100 chance of developing end stage renal disease, while this chance is only 1 in 600 for the healthiest individuals. Sometimes there are some psychological setbacks if the kidney donor learns that the surgery was unsuccessful or if the organ was rejected by the recipient's body later (these things occur rarely). The most severe risk to a living kidney donor is death happening in close association with the donation surgery which occurs in about 3 out of 10,000 living donors.

Sometimes kidney patients feel unable to accept a kidney from their own son or daughter because it may feel like they are taking life away from their child. But perhaps there will be an emotional health benefit to that son or daughter with this opportunity to give life to a parent.

How do you find a donor? It is not as rare and difficult as many people believe. The main matching criteria is blood group (also known as blood type).

The following chart explains the blood group matching:

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Transplantation - From Donor to Recipient (continued from page 4)

If Kidney Recipient is Blood Group Is:	Then the Donor must be in Blood Group:
O	O
A	O or A
B	O or B
AB	O, A, B, or AB

In addition to blood group, your transplant doctor will attempt to match you on as many as possible from a panel of six antigens with your potential donor kidney. Matching on as many of these six as possible increases the likelihood of transplant success, but you may be matched with a donor who only matches you on three or four of these antigens, for example. Genetically, the most likely match of all six antigens will be when your potential donor is a family member. Other matching criteria that will be maximized include: your medical urgency, tissue match, your waiting time, and geographic distance from the donor (because a kidney must be transferred from donor to recipient within 24-48 hours).

When you approach someone to ask them to consider donating: be yourself, be informative, be optimistic, make it bigger than yourself, highlight the benefits of being a living donor, and encourage action.

Donor Network West serves more than 13 million people in 40 counties in northern California and Nevada. Dr. Neidlinger is their Chief Medical Officer. The network receives referrals of donor organs from hospitals within their network, then processes the donation to facilitate an organ match. The network also performs outreach with the families of loved ones of the donor to let them know that their deceased has

blessed the recipients' lives.

DECEASED DONORS:

Who are deceased donors? They can be newborn babies or up to 80 years old. The average age is 40 years old, and the most common cause of death is stroke, though many donors are non-metastasized cancer patients or have diabetes or lung/heart disease.

Many people have inaccurate beliefs about volunteering to become an organ donor after death. These inaccurate beliefs include believing:

- If they are facing an end-of-life health problem, that their doctor will not try to save their life if they are an organ donor.
- That they will be "cut up" in a disrespectful way
- That they are "too old" or "too sick" to be qualified to donate.

None of these reasons should discourage anyone from choosing to be an deceased donor.

In contrast, sometimes a deceased donor's family makes the decision to donate that loved one's organ(s), and these are the very personal reasons most often behind that decision:

- Donation will bring life from the death of our loved one
- Our loved one previously expressed a desire to donate
- A family member needs this type of donation.

We applaud Dr. Neidlinger for her dedication and lifesaving medical work to those in need of an organ transplant. Thank you Doctor for your time and presentation. Contact Dr. Neidlinger at Nneidlinger@DNwest.org or 925-480-3116.

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

Board of Directors

Christie Chapman
Debra Elmore
Karen Soo Hoo
Bobby Neal
Matt Reeder
Linda Umbach
Walt Umbach
Marcus Wong
Phil Wyche

And to countless Speakers,
Sponsors, and Volunteers

Follow us on Twitter [@baakp](https://twitter.com/baakp), or go to twitter.com/baakp.



For those new to Twitter: it is a way for us to send out a short message, (or a "tweet"). It might be to share an inspiring news story, educational health tip, or updates about one of our past or upcoming meetings. You can read these messages anonymously-- or you can sign up for a Twitter account to tweet your own message and to follow us. It is simply another way to quickly network and connect.

BAAKP Support Groups

Did you know that BAAKP has support group sessions every month (except December)? You may be asking yourself why would I attend a support group? There may be many reasons for not wanting to attend a support group, however the most common are: I get enough dialysis “talk” at the center; I’m not on dialysis yet; I’m on a transplant list, that’s all the information I need; it will make me more depressed; and it is just a bunch of sick people sitting around talking and whining.

Well, you would be wrong! BAAKP support groups are a great place to meet other people like yourself: people who have the same concerns about kidney disease, to help you understand the process, adjust to dialysis, and how to keep a healthy diet. Our support groups attendees include people who are at all stages of kidney disease – CKD (chronic kidney disease), on dialysis, family support, caregivers, transplant recipients, even transplant donors. Additionally, family and friends attend the support groups to get a better understanding of what to expect with kidney disease.

One of the biggest advantages of attending a support group is that you’ll get support from other people who feel like you do or just to address some issues that you are going through. So many times, we think the way we feel (emotionally or physically) is “just me.” The realization that one or more in the group is experiencing the same issues as yourself is often a huge relief.

Sharing your feelings and talking about your situation can be very difficult for some. Our

support groups are a safe and supportive environment. This can be very therapeutic and healing. Again, you will find that others have been where you are now and it often helps to know you are not alone in this fight.

A benefit of support groups that might not immediately come to mind is your chance to help others. You can attend support groups as often as you want. We know it can be sometimes be difficult to attend depending on your schedule, however help is always available. Your attendance can affect others positively by letting others hear about your experiences and successes, making friends, and by your kind and caring demeanor. You will also notice that you feel better when you are able to help someone else.

The BAAKP support groups are also a great place to learn helpful information. BAAKP encourages everyone to be knowledgeable and proactive in their health care. You are your own best advocate. Between our two support groups, we have had at least 15 people go on to receive transplants. Many of these people credit BAAKP for giving them knowledge and support during their kidney journey. You can read some of their stories in back issues of our newsletters (located at www.baakp.org.)

We invite you to visit one of our upcoming support groups! Upcoming support group dates are on the back of this newsletter and you can always check our website for dates/times/places. No RSVP is necessary.



Oakland support group members



Palo Alto support group members

Who Are We?

Who are we? We are the Bay Area Association of Kidney Patients (BAAKP), a volunteer, non-profit group of kidney patients, their loved ones and medical professionals. We were founded in 2007 with the mission to EDUCATE and SUPPORT San Francisco Bay Area kidney patients.

The main activities of the BAAKP are:

1. Regular educational and support presentations held at Palo Alto Medical Foundation in Palo Alto and in Oakland. Meeting topics have included: the implantable bio-artificial kidney, home dialysis, and transplant programs at Stanford, UCSF, CPMC, and UC Davis.
2. Community education through local health fairs and talks at service clubs.
3. Our website at www.baakp.org has notices of upcoming events, current and past newsletters, videos of past educational presentations, and links to other kidney resources.
4. Our newsletter, *Kidney Konnections*, is published three times a year and is distributed by email and USPS mail.
5. Small support group meetings held 11 times a year at Palo Alto Medical Foundation in Palo Alto or in Oakland at Alta Bates Summit Hospital.

There are no charges for any of our activities; all are welcome! There are no dues or admission fees; we exist solely on donations and grants.

We invite you to join us — either in person at a support group meeting or educational presentation. You could become a member of our Board of Directors, or join us online through Facebook (www.facebook.com/baakp), Twitter, twitter.com/baakp or LinkedIn.

Thanks to our sponsors!

We wish to thank Satellite Healthcare and Wellbound San Jose for their generous support of the January 28, 2018 Educational Presentation and the videography as well. And thank you Ms. Patrice Smith of Satellite for your contributions to this event. (See www.baakp.org for videos.)



2018 BAAKP Board of Directors

Top L to R: Karen Soo Hoo, Bobby Neal, Phil Wyche, Matt Reeder, Bottom L to R: Marcus Wong, Debra Elmore, Linda Umbach, Walt Umbach. Missing is Christie Chapman

BAAKP Concludes Successful End-of-the-Year Fundraising Campaign

Thanks to a very generous anonymous matching donor member, BAAKP was able to raise \$9665.00 with the combined Giving Tuesday and End-of-the-Year Fundraising Campaigns. Your donations enabled our non-profit 501(C)3 organization to not only celebrate our 10 year Anniversary in 2017, but look forward to many more years in the future.

Now that you have helped us, please let us know how we can help you!



In the News... A New World's Record!

A chain of kidney transplants that began with an altruistic donor at the University of Alabama at Birmingham in December 2013 ended on January 1, 2018 with a total of 88 total transplants. The UAB Kidney Chain grew through the generosity of paired donors and 18 altruistic donors. There are approximately 6,000 living donor transplants per year in the United States.



Bay Area Association of Kidney Patients

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Educating & Supporting Kidney Patients!

Please visit our website at
www.baakp.org
to make a donation, see back is-
sues of our newsletters, and view
videos of our past meetings. Your
help is greatly appreciated!



SAVE THESE DATES !

Peninsula Events

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

Educational Presentation: 1-4 pm

- **May 20, 2018**

Support Group Meetings: 1-3 pm

- **April 8, 2018**
- **June 10, 2018**

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

- **May 6, 2018**
- **July 22, 2018**

Board of Directors' Meetings **1st Tuesday of the month**

6:00 pm

info@baakp.org (650) 323-2225

Mark your Calendars! May 20, 2018 **Transplant & Eating with Kidney Disease**

On Sunday, May 20, 2018, our Educational Presentation will feature two special speakers. **Vanessa Grubbs, MD, MPH**, Associate Professor, Division of Nephrology, University of California, San Francisco will discuss her own love story and experience with attempts to secure a kidney transplant, all of which she detailed in her book, *Hundreds of Interlaced Fingers: A Kidney Doctor's Search for the Perfect Match*.



Also joining us that day will be **Lauren Levy, MS, RDN, CSR**, Satellite Health Lead Nephrology Dietitian for the SF Peninsula territory. Ms. Levy will share tips for enjoying good food during all stages of Chronic Kidney Disease.

Reserve your seat now for this event on May 20, 2018, to be held from 1-4 pm at the Palo Alto Medical Foundation, 3rd floor, 795 El Camino Real, Palo Alto, CA 94301. Go online to <https://tinyurl.com/BAAKP-May2018> , email us at info@baakp.org or call 650-323-2225.

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