

Kidney Konnections

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Bay Area Association of
Kidney Patients
Affiliated with the National Kidney Foundation

The Bay Area Association of Kidney Patients is an all-volunteer, non-profit organization formed to educate and support Bay Area kidney patients. The BAAKP is affiliated with the Northern California Chapter of the National Kidney Foundation.

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October Meeting Focused on Dialysis Options

By Grant Bennett

We at the Bay Area Association of Kidney Patients were very pleased to have as our guest speaker, John Moran, MB, BS, Sr. VP, Clinical Affairs, Satellite Dialysis, Corporate Medical Director, Well-bound at our October 2009 meeting. Accompanying Dr. Moran were Deborah Kurland, LCSW, Carol Elwood, RN, as well as a panel of patients.

Dr. Moran is very well versed in the treatment of end-stage kidney disease and made a very concise, informative presentation outlining the various options (also called modalities) open to patients who need to have dialysis.

Dr. Moran went over the two most frequently used modalities for dialysis: hemodialysis and peritoneal dialysis. Hemodialysis is the removal of waste products and fluid from the blood by the insertion of needles into a vein and then passing the blood past a very thin membrane, allowing the waste products and fluid to pass out of the blood. The cleansed blood is then returned to the vein. Hemodialysis usually takes 3 to 5 hours per treatment, and is usually performed 3 times a week.

Peritoneal dialysis is the process of adding special fluid into the patient's abdominal cavity through a permanent catheter. The fluid then collects the waste products passed across the

Dr. Moran described the two modalities in detail and was able to show data reflecting that the more frequently a person dialyzes, the healthier the person is and feels. It



John Moran beside two home dialysis machines: the Home Choice PD Cycler and the NxStage Home Hemodialysis System

seems the ability to maintain an average of low levels of blood waste and excess fluids improves a person's overall energy, positive mental outlook, appetite, and general health.

Most insurance will not cover in-

center hemodialysis more than three-times-per-week. The alternative is peritoneal dialysis. This is a very good substitute for hemodialysis and has excellent results, but it does require the person to "exchange" their special dialysis fluid several times a day (CAD-Continuous Ambulatory Dialysis), which is not always an acceptable alternative for some people. That is until now.

With the advent of nighttime peritoneal dialysis (also called nocturnal PD), all the exchanges are con-

peritoneum (the abdominal peritoneal membrane), then the patient discards the fluid, removing the waste products with the fluid. Peritoneal dialysis is usually performed several times a day, every day.

In the United States, 93% of dialysis patients are on in-center hemodialysis and only 7% choose peritoneal or home hemodialysis. About 80% of home dialysis patients choose peritoneal dialysis, for the freedom, simplicity, fear of needles, ability to travel and patient control.

(Continued on page 2)

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stantly performed (called cycling) while the person is at home, or even sleeping. This can be done 6 nights a week, is more flexible (it can be short one night, long the next), allows for a more complete cleansing of the blood, and does not take time from the person's waking life.

Another new alternative has come about in the form of new home hemodialysis machines. The new hemodialysis machines are more compact and easier to use, require much less modification to the home than the in-center hemodialysis machines, and can be operated by the patient and a partner following in-depth training on machine operation and patient connection/removal to/from the machine. These units are used at home for a few hours a day, usually in the evening, and can be used every day or on a schedule that suits you. With advanced preparation, you can even travel with the equipment on vacation or business trips. Dr. Moran stated that "if you can drive a car, you can do home hemo."

These various ways to dialyze have many advantages and disadvantages, some medical and some social, all of which need to be discussed with your partner, your family, and your doctor to find the one that suits your lifestyle best.

We thank Dr. Moran for the wealth of knowledge and experience that he imparted to our group. We wish him the best and hope to see him again.

This newsletter is not intended to be a substitute for advice from your medical professionals. Please consult your physician or other medical professionals about any changes or additions you make to your kidney care.

Spotlight on Dialysis: Options

As a part of our October meeting, Carol Elwood, RN and Clinical Nurse Manager, at Wellbound told us about an "Options" class she teaches at Wellbound and briefly explained the options available to someone with renal failure.

Ms. Elwood told us that there is no one "right" choice when it comes to dealing with end stage renal disease, but there are five options:

1. Do nothing
2. In-center Hemodialysis — Usually performed 3 times a week
3. Peritoneal Dialysis (PD) — There are two types: Continual Ambulatory Peritoneal Dialysis (CAPD) which is performed 4 times a day and PD Cyler which occurs at night.
4. Home Hemodialysis — Usually performed more than 3 times a week
5. Kidney Transplant

During the talk, Ryan Ferguson from NxStage showed us the NxStage Home Hemodialysis machine and explained how it is used. There was also a Home Choice PD Cyler displayed and its use was discussed too. The audience seemed surprised at how small and portable both the machines were.

Ms. Elwood holds Options classes at Wellbound once a month and anyone is welcome to attend. The following resources are available for more information:

www.homedialysis.org
www.nxstage.com
www.Wellbound.com

Other Local Kidney Support Groups & Meetings

<p>Patient Support Group</p> <p>Open to all pre-dialysis, dialysis, pre-transplant, and transplant patients, friends, and family</p> <p>Meets at 1 pm the second Saturday of every odd month at: Kaiser Permanente-Santa Clara Hospital Building, 700 Lawrence Expressway, Santa Clara, CA</p> <p>Contact: Lorraine Maloon, LCSW 408-851-1044</p>	<p>T.R.I.O Transplant Recipients International Organization</p> <p>Silicon Valley Chapter Meets on the 2nd Thursday of each month at 7:30 pm. El Camino Hospital, Cafeteria Meeting Room, 2500 Grant Road, Mountain View, CA 94040 www.bayareatrio.org 408-353-2169</p>	<p>San Francisco Polycystic Kidney Foundation</p> <p>For general PKD information, call: 1-800-PKDCURE</p> <p>For information about local groups, go to: www.pkdcure.org/sanfranciscochapter</p> <p>For chapter specific questions, please send email to: sanfranciscochapter@pkdcure.org</p>	<p>The National Kidney Foundation of No. California & No. Nevada</p> <p>Has many resources available and sponsors many events. For more info: www.kidneyca.org 415-543-3303</p> <p>National Kidney Foundation www.kidney.org</p>
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Spotlight on Dialysis: Panel Discussion

Also at our October meeting, a very interesting panel discussion took place about different dialysis options. Moderated by Deborah Kurland, LCSW (Nephrology Social Worker) at Wellbound, each panelist shared their story and told what form of dialysis they were on. Below is a brief synopsis of each panelist.

Patty, a speech pathologist, has been on PD (peritoneal dialysis) since 2004. She is currently on a PD Cycler. She likes the flexibility the Cycler gives her.

Tim does home dialysis in the evening and nocturnal dialysis every other night. He has found that he has more energy and feels in control of his life again.

Cindy, Tim's wife, talked to us about being Tim's dialysis partner and helper. She feels it takes a real partnership to do home dialysis, but it has improved their quality of life.

John is on PD and recently made two overseas trips to Australia and Europe. He affirmed that even while on PD "you can continue to enjoy travel."

Gail, an HR manager in San Francisco, is also on a PD Cycler. She likes the "normality" PD allows her.

Eric is on home dialysis with every other night nocturnal dialysis. He enjoys the freedom to spend time with friends and is "enjoying my life a lot more these days."

Nelson, the father of a new baby, performs home dialysis 6 days a week. He chose this method as it helps him maintain better blood values and also requires less attention to diet and fluid intake.

We'd like to thank Deborah and our panelists for taking the time to come and speak to us. We found it very enlightening!



The Dialysis Panel

Thank You to Our Participants and Sponsors!

Thank you Dr. Moran, Deborah Kurland, and Carol Elwood from Wellbound. Also thanks to Ryan Ferguson from NxStage for bringing the dialysis machines and a special thank you to our wonderful kidney panel participants.

Our thanks also go to our sponsors of this event: Wellbound with a generous \$500 donation to help cover our expenses, Genzyme for their continuous support, Nick Sharma of The Willows Market for donating the speaker's gourmet gift basket, and Bella Day Spa for donating manufacturers' samples. And a special thank you to the Palo Alto Medical Foundation for providing the fabulous venue for our events!

www.Wellbound.com

www.Genzyme.com

www.NxStage.com

www.pamf.org

www.Willowsmarket.com 60 Middlefield Rd, Menlo Park, CA 94025

Bella Day Spa, Linda Marocco, 1916 El Camino Real, Atherton, CA (650) 322-2042

Today's Joke



Another proudly functioning kidney transplant.

Cartoon by Peter Quaife, a Canadian dialysis patient
From his book [The Lighter Side of Dialysis, Volume 1](#)
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BAAKP Gets Around!

2009 was a busy year for the Bay Area Association of Kidney Patients! In addition to our quarterly meetings, our members have participated in various public education health fairs and public events.

We were invited by the National Kidney Foundation to have a booth at the **NKF San Francisco Kidney**

Walk where we featured our "Buffet of Choices," a mini quiz of dietary choices for the Chronic Kidney Disease patient. Grant Bennett and Walt and Linda Umbach manned the booth. We also had a booth and were walkers at the **NKF Silicon Valley Kidney Walk**. Anne Griffin, Debra Elmore, Brad Price, Grant Bennett, Jeanne Heise, Bea Goodman, Ben Lee, Ryan Barr, Ed & Sherry Leon, Melissa Boccia, and Kristy Zmek all helped with that event. The Silicon Valley Kidney Walk was our major fund raiser of the year; thanks to all who helped us exceed our goals.



The Buffet of Choices

Runners' High in Menlo Park (now called Fleet Feet) sponsored a special BAAKP Day in May; when you made a donation to our BAAKP 2009 walk fund, you received a 10% discount on athletic apparel or footwear. PLUS, Runners' High donated another 10% to the walk fund. Thank you Jim Gothers for your wonderful support! Members who manned the booth were Jeanne Heise, Grant Bennett, Linda and Walt Umbach (& Colleen), and Doris Nissinoff. We featured our Buffet of Choices and discussed kidney disease with strollers on Santa Cruz Avenue.



Colleen helps out at Runners' High

BAAKP also participated in the **Soul Stroll**, a large health fair at Coyote Point Park in San Mateo. This event was co-sponsored by Mills Hospital and the African American Community Health Advisory Committee. In addition to the Buffet of Choices, we had a large poster that highlighted our organization and we distributed literature and our newsletters. There were over

3500 attendees walking, dancing, and exercising, each of whom had a card that the BAAKP booth attendants had to sign! Members who helped with our booth were Anne Griffin, John Hatfield, and Debbie Kurland.

And the following month, BAAKP participated in the **ACLF Health Fair** which took place at the Abundant Life Christian

Fellowship in Mt. View on a Saturday and Sunday. This is an annual health fair at the Church. BAAKP volunteers who helped at that event were Anne Griffin, Debra Elmore, Phil Wyche, Debbie Kurland, and Maria Retana.

As you can see, it was a busy and fun year! If you know of events that the BAAKP should participate in, or if you would be interested in helping us at an event, please email us at bay.area.kidney@gmail.com or call us at 650-323-2225.



Anne Griffin, Deborah Kurland, and participant at the Soul Stroll

BAAKP Steering Committee Elects New Officers

At the October meeting of the BAAKP Steering Committee, Linda Umbach stepped down as President after serving a two year term. Grant Bennett was unanimously elected to serve as the new President of BAAKP for the next two years.

Listed below are the current officers and their positions:

- Ryan Barr – Graphics Designer
- Grant Bennett – President, UCSF Liaison, Videographer, Co-Webmaster
- Debra Elmore – Newsletter Editor, Co-Webmaster
- Bea Goodman – Hospitality
- Sam Goodman – Planning
- Anne Griffin – Development
- John Hatfield, PhD – Librarian
- Jeanne Heise – Correspondence Secretary
- Scott Kessler – Program Manager
- Marco Martin – Hispanic Liaison, Database Manager
- Linda Umbach – Program Manager, Co-Webmaster
- Walt Umbach – Recording Secretary
- Phil Wyche – Hospitality

At our November meeting, Ryan Ferguson was approved as the newest member of the Steering Committee. Ryan is the Northern California Area Manager at NxStage and works with several dialysis clinics to provide education and support for patients on dialysis.

The Steering Committee plans and hosts the programs at our quarterly meetings, takes part in educational events and health fairs, provides information and support to kidney patients and their families, and in general determines who the BAAKP is and what we do.

The Steering Committee still has positions that need to be filled and we are always looking for new members.

If you would be interested in becoming a member of the Steering Committee, please talk to any Steering Committee member at our meetings or contact us by email (bay.area.kidney@gmail.com) or telephone (650-323-2225). Besides knowing you are helping fellow kidney patients, being a Steering Committee member is fun, too!

H1N1 Virus Infection Update for Kidney Patients

Also on October the 11th, we were happy to welcome Alexandra (Sasha) Madison, MPH, CIC, Manager, Infection Control and Epidemiology Department, Stanford Hospital and Clinics, who explained various aspects of the H1N1 virus infection and how it affects kidney patients.

Ms. Madison stated that the H1N1 flu affects mostly the young (only 5% occurs in persons older than 50). Pregnant women and people with asthma/COPD, diabetes, immunosuppression (e.g., chronic steroids or transplant patients), pulmonary disease, renal failure, and chronic liver disease are at a higher risk. Those over 60 may have some partial immunity, but should still take all the precautions to avoid getting infected!

Symptoms of H1N1 infection are similar to seasonal flu infection: fever of 100 degrees Fahrenheit or more, and any one or more of the following: cough, sore throat, nasal congestion or runny nose, body ache, headache, and chills. All kidney patients should call their nephrologists or transplant clinic when a fever and such symptoms appear; you cannot be too cautious.

Regarding the H1N1 vaccine, kidney transplant patients should be especially aware. The nasal vaccine (a live attenuated virus vaccine) is not recommended for patients who are immunosuppressed. Also be aware that, with the nasal vaccine, the virus can be active and transmitted for 7 days or more after the vaccine is administered. And remember to get **both** the seasonal flu and H1N1 flu vaccines. The two vaccines protect you from two different viruses, so one vaccine will not protect you from the other.

H1N1 is transmitted the same way as the seasonal flu. Flu viruses are usually spread from person to person through sneezing or coughing. Some people may become infected by touching something that has virus on it and then touching their nose or mouth.

In addition to using hand sanitizers and washing your hands frequently, Ms. Madison suggested using a surgical mask to protect yourself in crowded situations with strangers and especially when traveling. You can use the regular mask available over the counter and do not need the special N-95 mask recommended for medical professionals.

***Educating and
Supporting Bay Area
Kidney Patients***

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Please visit our website at
www.BAAKP.org
for back issues of
our newsletters and videos
of our past meetings!

*Newsletter publication dates are November, February, May and August
If you've received an extra copy of this newsletter, please pass it along!*

***SAVE THESE DATES!
General Meetings:***

- **January 10, 2010**
**Post Kidney Transplant
Care with
Dr. John Scandling**
- **March 14, 2010**
**Auto-immunity and
Kidney Disease with Dr.
Mark Genovese**
- **May 23, 2010**
**Understanding Your Lab
Results with Dr. Carrie**

***Steering Committee
Meetings***

**Second Wednesday of
every month at 6:00 pm**

*If you would like to join us in the
leadership of this group, we would
love to have your help.*

(Call for location)

***bay.area.kidney@gmail.com
650-323-2225***

**January 10, 2010 Meeting Features
John Scandling, MD and the
Stanford Kidney Transplant Team Discussing
Post Kidney Transplant Care**

The Bay Area Association of Kidney Patients is pleased to announce the topic for the Winter quarterly meeting. Our featured speaker will be John Scandling, M.D., Medical Director, Adult Kidney & Pancreas Transplant Program.



Dr. Scandling will be accompanied by the Kidney Transplant Team from Stanford Hospital and Clinics. They will discuss how transplant patients can assist in preserving their transplanted kidneys. Post-surgical questions, causes of organ rejection, medications, clinic visits, pregnancy and blood tests are among

the topics to be covered.

This FREE EVENT will take place from 1:00 to 4:00 pm on Sunday, January 10, 2010 on the 3rd floor of the Palo Alto Medical Foundation, located at 795 El Camino Real, Palo Alto, CA 94301. There will be ample time for audience questions and for social interaction and patient support. Kidney-friendly refreshments will be served.

For reservations, email us at bay.area.kidney@gmail.com or call us at 650-323-2225. You may also fax your reservation to 650-327-0178 or mail to BAAKP, Box 2332, Menlo Park, CA 94026.