

Kidney Konnections

A publication of the

Volume 2, Issue 2

February 2009
Winter 2009 Issue



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 San Francisco Chapter of the National Kidney Foundation

For questions or comments about this newsletter:

bay.area.kidney@gmail.com

Or by mail to
P.O. Box 2332
Menlo Park, CA 94026 2332

Chapter Officers

Linda Umbach,
President

Walter Umbach,
Recording Secretary

Jeanne Heise,
Corresponding Secretary

Sam Goodman, PhD,
Treasurer

Ryan Barr, *Graphics*
Patrick & Tomomi Barron
Videographers

Grant Bennett, UCSF
Liaison

Betsy Bucter, R.N.,
CPMC Liaison

Debra Elmore,
Newsletter Editor

Bea Goodman,
Hospitality

Toby Gottheiner, M.D.,
Medical Advisor

Anne Griffin,
Development

John Hatfield, PhD,
Librarian

Scott Kessler, *Programs*

Ben Lee, *Website*

Ed & Sherry Leon

Brad Price, *NKF Liaison*

Phil Wyche, *Hospitality*

Stanford Transplant Team Outlines Adult Kidney and Kidney/Pancreas Transplant Programs

By Jeanne Heise

More than 70 audience members were lucky enough to have six members of the Stanford transplant team, lead by transplant surgeon Dr. Marc Melcher, present an overview of the transplant process at the BAAKP January 2009 meeting. The presentation covered the referral process, pre-transplant and waiting list process, psychosocial aspects of transplant, and transplant surgery. The current Adult Kidney Transplantation Program at Stanford was established in 1991. Since its inception, over 1000 transplants have been performed at Stanford.

Referral Process: Patient referrals are initiated by nephrologists, patients, or dialysis units. Any patient with a GFR of 20 or less or already receiving dialysis is eligible for listing if considered a suitable candidate by the evaluating transplant center. The first point of contact for prospective recipients is the Patient Care Coordinator. The Patient Care Coordinator gathers insurance information, medical history, and patient demographics. Various members of the transplant team then work to secure insurance approval and help the patient complete the preliminary medical and psychological evaluations necessary as requested by the transplant programs.

Not everyone qualifies as a can-

Waiting List: Once a patient is considered a suitable candidate for transplantation, their name is placed on the waiting list with the United Network for Organ Sharing (UNOS). The California Transplant Donor Network (CTDN) is responsible for allocating organs from donors in our region to patients at Stanford, CPMC, and UCSF. These organs are offered to patients based on the ABO blood type, the length of time on the waiting list, and a negative cross-match. Kidneys outside our region may also be allocated to patients in our region if they are a perfect match. Currently, the average wait time for unsensitized patients in our region can vary between five to eight years depending on the blood type of the recipient with blood group O and B having longer wait times.

Extended criteria kidneys are also available for patients over 60 years of age or those with a long history of diabetes over the age of 50. Extended criteria kidneys are deceased donor kidneys that for medical reasons do not meet the stringent requirements for regular transplant, but are still viable organs. The wait time for extended criteria kidneys is much shorter.

While on the Stanford waiting list, patients are expected to submit monthly blood draws; report hospitalizations, surgeries, transfusions, and changes in health status; and keep demographic and insurance information up to date. It is always a good idea for patients to stay in contact with their



Norma Guerrero & Dr. Marc Melcher

Note: Different transplant programs may have different policies and procedures regarding transplantation process. The information presented at the meeting and in this article is specific to Stanford.

didate for transplantation. In particular, those with active infections, cancer, a HIV positive status, advanced heart disease, peripheral vascular disease, morbid obesity, psychosocial issues, and multiple organ failure may not qualify.

(Continued on page 2)

(Continued from page 1)

Patient Coordinators and to check in on a regular basis.

While on the waiting list, the patient is also encouraged to recruit potential live donors. In order to qualify as a live donor, individuals will need to prove an established relationship with the recipient, be mentally competent and demonstrate free will, be a compatible blood type, be at least 18 years old, and be in good mental and physical health. If the potential healthy and willing donor is incompatible with the patient, they still may be able to help the recipient get a transplant sooner by participating in Stanford's donor chain or paired donor exchange programs.

Psychosocial Aspects of Transplant During the transplant evaluation, patients are assessed by a social worker regarding family background, support systems, adjustment to illness/dialysis, education, psychiatric history, substance use history, knowledge of their illness, history of compliance, and expectations and concerns regarding their potential transplant.

Both the time on the waiting list and the transplant itself have an enormous emotional impact on the patient. These impacts include: financial hardships, medical set backs, medication side effects, increased levels of stress, increased levels of responsibility and decrease of independence, changes in family dynamics, adjustments to new life patterns, and, eventually, even the return to wellness after years of sickness.

The social worker and the psychiatric team can provide education and referrals to those on the waiting list and to those who have received a transplant. There are also a variety of support groups available including TRIO (transplant support group), caregiver support groups, and Partnership for Prescription Assistance (to qualify to receive medications directly from pharmaceutical companies).

Getting Transplanted Transplantation is the most effective treatment for kidney disease available today. Unfortunately, donors and organs are scarce, the allocation system is not completely perfect, and there may be many immunological incompatibilities between donor and recipients.

Stanford continually searches for ways to increase the chances for transplant either through improving recipient health or expanding the donor pool. Currently Stanford has a program that offers gastric bypass surgery to those seeking transplant, but are disqualified because of obesity. Those patients who go through gastric bypass surgery may be added to the transplant list one month after their surgery, and be transplantable 6 months after (if their BMI is less than 35).

Stanford is also actively promoting more live kidney donation. The hospital does everything possible to protect the donor, to provide donor advocates, to protect donor privacy and confidentiality, to provide donors with their own medical team, and to ensure good communication.

Multiple strategies are needed to increase the number of available organs. In cases of incompatible donors, paired kidney donation, domino or donor chains, and desensitized incompatible donations are available options. While these methods often pose ethical, legal, and logistical challenges, the benefit of increasing the pool of available organs for transplant is obvious. It is the challenge of transplant programs to balance the needs of individuals against the needs of society, the opportunity to maximize individual life spans against the collective life span.

Stanford Transplant Team: 650-725-9891

Norma Guerrero, *Patient Care Coordinator*
Tania Makki, *Pre-Transplant Coordinator*
Bradie Hadfield, *Clinical Social Worker*
Dr. Marc Melcher, *Assistant Professor of Surgery, Transplant Surgeon*
Mojgan Haririfar, *FNP Manager*
Ana Simos, *Diabetes Educator*

Note: The Stanford Transplant Team will return in January of 2010 to complete their presentation with the subject of

Post-Transplant Care

Other Local Kidney Support Groups & Meetings

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.

**T.R.I.O
Transplant Recipients International Organization**
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

**Contra Costa Dialysis Support Group
"Patients Helping Patients"**
4th Tuesday of each month
January - October
Carl's Junior Restaurant
2280 Oak Grove Rd
Walnut Creek, CA
Contact: Tom and Kathie McClish (916) 332-1086 OR Paul and Marie White (925) 934-4883
For: Dialysis patients and their loved ones, staff members

The National Kidney Foundation
(NKF) of Northern California has many resources available and sponsors many events.
For more info:
www.kidneyca.org
415-543-3303

National Kidney Foundation
www.kidney.org

Living Well With Kidney Disease

By Linda Umbach

This is the first in a series of articles about living with kidney disease. Send us your own tips and tricks; we will feature them in our next issue! Email at bay.area.kidney@gmail.com or mail to BAAKP, P.O. Box 2332, Menlo Park, CA 94026-2332.

There's no denying that having Chronic Kidney Disease is a long haul. Maybe that's why they call it "Chronic"!

The best way to deal with something you face daily is to take charge; be your own inspiration. You must try to control Chronic Kidney Disease. Don't be passive. And don't expect the doctors and nurses to closely supervise your daily care. They have too many patients, too little time, and the reality is that insurance limitations reduce their contact time with a patient. Depend upon the medical personnel for what they do best: balance your medications and bring you the latest in medical knowledge.

As a person in charge of your own health care, there are many important jobs you, as the patient, can do:

Know your labs: Always ask for a copy of your laboratory tests and keep them on file. Look for trends! Learn to read the results and if you don't understand them, ask your doctor or dialysis nurse. If a lab value changes abruptly, find out why. Use your knowledge of your lab values and diet to learn how to bring down the Potassium (K) or Phosphate (P) numbers — make it a game and a challenge to get those values closer to normal.

Know your meds: Be informed about all your medications, dosages, and side effects. Keep a list of your current prescriptions and dosages with you at all times! You never know when you will need them — perhaps in a strange emergency room!

Follow that ?%+@/*^# chronic kidney disease diet: Sure, we all gasped when we first heard about diet limitations in CKD. But the reality is that many medical professionals (and patients too!) know that close attention to your diet can help delay the progression of CKD. What, only white food? Only white bread, cream cheese, and cream of rice cereal? No whole wheat bread, regular cheeses, and Wheaties? Yes and no. If you dig more deeply, you will see that there is a lot of variety; all is not lost! Maybe an appointment with a Renal Dietician would reveal this important information. There are numerous kidney-friendly recipes out there. For help with diets, menus and recipes, start with the National Kidney Foundation (www.kidney.org) and the American Association of Kidney Patients (www.AAKP.org), then look to other kidney providers, DaVita Dialysis (www.davita.com) being one. Most importantly, treat yourself. Yes, you can't have potatoes too often, and rice and noodles become boring, but use good noodles — not those dried up, year-old things in a bag, but fresh noodles from the gourmet department! Remember, you're saving money by eating only small amounts of expensive protein. Live it up with what you can eat!

Attend local support groups: Talk with people who are also dealing with kidney disease. Try to attend our quarterly Bay Area Association of Kidney Patients meetings. Even though the current topic might not interest you, you will always learn something! Check our website for meeting dates: www.BAAKP.org. Chances are you will meet someone at a meeting that is dealing with the same CKD issues you are! TRIO sponsors monthly meetings for transplant patients; see www.TRIO.org for the national website and www.bayareatrio.org for the local Bay Area chapter.

Part 2 of this article will appear in our May newsletter.

Design Firm Donates New Logo to BAAKP

You may have noticed the "new look" to our current newsletter, flyers, and letterhead! Thanks to Steven Umbach and his associates at Umbach Consulting Group, we have a bright new logo. Working with the collaboration of the Steering Committee of BAAKP, they designed the logo, font type, and colors, tailoring the result to the goals of the Bay Area Association of Kidney Patients. Progress is measured in steps and this is a BIG ONE! Thanks, Steve and group for the donation of your time! Umbach Consulting can be reached at (936) 273-4342 or www.umbach-cg.com

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

Post Office Box 2332
Menlo Park, CA 94026-2332

Phone: 650-323-2225

Fax: 650-327-0178

Email: bay.area.kidney@gmail.com

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!*

**March 29, 2009 Meeting will spotlight
The Causes of Kidney Disease: Part I, Diabetes**

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

- **March 29, 2009**
**The Causes of Kidney
Disease; Part 1: Diabetes**
- **June 6, 2009**
**BAAKP Fundraising
Walk in San Jose**
- **June 7, 2009**
**The CKD Diet:
The Importance of
Phosphate Control
with
Luis Alvarez, MD, Phd.**

***Steering Committee
Meetings***

**Second Wednesday of
every month at 6:30 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

The Bay Area Association of Kidney Patients is pleased to present Dr. Vivek Bhalla, Assistant Professor of Medicine at Stanford University, and an expert on diabetes and kidney disease. Dr. Bhalla will address the differences between patients with Type 1 and Type 2 diabetes, management of pre-dialysis chronic kidney disease in those with diabetes, and specific issues that diabetic patients face.

Joining Dr. Bhalla will be Connie Schroepfer, Renal Nutrition Specialist at San Francisco General Hospital and Children's Hospital and Research Center in Oakland. Ms. Schroepfer has vast experience working with patients undergoing hemodialysis and peritoneal dialysis, and has additional spe-



cialized knowledge in urea kinetics, vitamins, and minerals.

Both speakers will address diabetic kidney disease in practical terms and provide ample opportunity for questions.

The meeting will take place from 1:00 to 4:00 p.m. on Sunday, March 29, 2009 at the Palo Alto Medical Founda-

tion, located at 795 El Camino Real, Palo Alto, CA 94301. The event is free. Kidney-friendly refreshments will be served. The meeting also features time for social interaction and patient support.

To reserve your seat, 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 94026-2332.