Kidney Konnections

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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. Visit us at **www.baakp.org**

The Journey to a Kidney Transplant

The year 2012 began with a familiar subject. Our January 22, 2012 presentation detailed the all important topic of the kidney transplant (generally the best option for an ESRD kidney patient). Three professionals, an altruistic donor and her recipient joined us for this important event.

Ms. Kathy Clark, Volunteer Program Manager and herself a transplant recipient, from the California Transplant Donor Network (CTDN) described the role of CTDN in the transplant world. CTDN is a non profit organ and tissue procurement organization headquartered in Oakland, CA. There are over 175 hospitals in their service area providing organs to the four transplant hospitals within the Bay Area: Stanford, Lucille Packard Children's Hospital, UCSF, and California Pacific Medical Center.


Kathy Clark from CTDN speaks about the importance of kidney donations

CTDN focuses on community & hospital education, facilitating the recovery of organs from deceased donors, and working with potential donor families. There are over 89,000 people waiting for kidneys organs across the county with 8,000 people waiting in Northern and Central California. Out of about 2.6 million potential donors who pass away annually in our country, only about 7,000 actually become donors of any type of organ.

Once CTDN determines that the patient will become a donor, the staff places organs by submitting donor information to UNOS (United Network for Organ Sharing) electronically. A program matches the donor to potential recipients, wait-listed by organ, based on complex ***prioritization algorithms which also account for wait time.*** CTDN then contacts surgeons by their patient's ranking on the "list". The surgeon for the selected recipient is given an "offer" and the potential recipient notified. (**Yes, those phone calls do come in the middle of the night!**). If the offer is accepted by the surgeon and the recipient, other members of the transplant team are immediately notified. Transplant centers have one hour to accept a kidney offer and then recovery is scheduled. Donated organs are transported to the transplant centers where the patient is waiting.

To save more lives, CTDN encourages donation by working with Donate Life Ambassadors: recipients, donor families and patients on the waiting list. They share their stories in their communities and encourage people to say "yes" and register on DMV California Registry or online at www.donateLIFEcalifornia.org.

Ms. Mee Lee, RN, CCTC, Pre-Transplant coordinator with Stanford's Kidney Transplant Program reviewed the basics of the kidney transplant process. At the evaluation appointment, the candidate's medical and psychosocial history and the risks and benefits of transplantation are determined. If the benefits outweigh the risks, one is accepted for transplantation and may be added to the UNOS list. While on the waiting list, the patient is in either "active "or "inactive" status. **In both statuses you are accruing time**, but you are eligible to receive a kidney transplant offer only when your status is "active". Your status becomes active once you have completed testing or resolved any medical, psychosocial, or insurance issues You may be on multiple lists at the same time, but in different regions. And if you transfer to another hospital within or out of region, you can take your earned wait time as well. (**Getting on that list ASAP is very important!**) Currently, the average wait time in the CTDN region for a deceased donor kidney is about five to eight years. This varies by blood type; the most common blood type O has the longest wait time of 7-8 years.

Stephan Busque, MD, MSc, FRCSC is the Director of the Stanford Adult Kidney and Pancreas Transplantation Program. He reviewed the basics of kidney compatibility, blood group compatibility and HLA antigen compatibility (there are 6 HLA antigens on our blood cells to match), and why cross matching is important. Patients wait so long for a kidney and then, after receiving a kidney, have to take immunosuppressants (anti-rejection medicines), with their side effects, for the life of the kidney.

Now, in new research, Dr. Busque's team is studying **Tolerance Induction**, applicable to kidney transplant recipients with living related kidney donors. We all have molecules, known as HLA antigens, on the surface of our cells that identify us. Given a transplant, our immune system detects foreign HLA (Human Leucocyte Antigen). These antigens on the new kidney are targeted for destruction with a class of antibodies known as anti-HLA. In this research, the patients' bone marrow is irradiated and the donor's stem cells infused to create a "chimera" or mixing of parentages of the patient's cell population. The doctors are hoping to "trick" the recipient's immune system to recognize these new antigens as "self" and avoid any attempt at destruction. They used this technique with 12 adult patients over the course of a few years. In all, 8 patients have been weaned from their immunosuppressants for more than a year. Three patients remain on drugs but are doing well.

M.C. Marco Martin with Dr. Stephan Busque and pre-transplant coordinator Ms. Mee Lee

Another "tool" for the Stanford physicians is the use of sophisticated **desensitization** procedures for the kidney patient who has very high anti-HLA antibody levels, which would prevent "matching" with a high percentage of potential kidney donors. They use the "**High Dose IVIG Protocol**" which involves pre-treatment with IVIG resulting in reductions of anti-HLA antibodies. So far patients successfully desensitized have enjoyed transplant survivals of 100%.

A third technique is the use of **paired exchanges** of kidneys. If there are two patients and two potential living donors and Patient One has blood type A and Donor One has blood type B, they are very incompatible. A second couple with Patient Two (Blood type B) and Donor Two (Blood type A), are also incompatible. A simple exchange of donors and recipients solves the problem. More elaborate exchanges and chains have occurred, involving as many a 30 donors and 30 recipients, with kidneys being transported all over the US. Altruistic (Good Samaritan) donors can play a huge part with the ability to start such chain donations.

Such an altruistic donor, **Ms. Kristine Enea**, told her story of donating a kidney to a woman she had not previously known. Both donor and recipient spoke and the attendees were quite curious about what inspired Kristine to donate. Kristine illustrated the caring spirit in all of us as human beings and how one person can make a difference.

Thank You to Our Speakers and Sponsors!

We wish to extend a huge Thank You to our speakers -**Dr. Stephan Busque** and **Ms. Mee Lee** from the Stanford Kidney Transplant Program (650-725-9891) and **Ms. Kathy Clark** from the California Transplant Donor Network (Kclark2@ctdn.org). Special thanks go to altruistic kidney donor Kristine Enea and her recipient for appearing and answering our questions. The more we know about our transplant options, the healthier we will be.

We are grateful to **Sigona's Farmers' Market** (2345 Middlefield Road in 2345 Middlefield Road Redwood City and Stanford Shopping Center at 180 El Camino Real, Palo Alto) for the beautiful gift baskets for the speakers. Also appreciated are the door prizes of a $25 Gift Card from **Safeway** (525 El Camino, Menlo Park), $20 gift certificate from **Shine Masters Car Wash & Detail** (701 Marsh Road, Menlo Park) and a free membership in the **American Association of Kidney Patients** (www.AAKP.org). And as always, a special thank you to the professionals at the **Palo Alto Medical Foundation** for providing the ideal venue. Please visit our sponsors and thank them for their participation.

Bay Area Association of
Kidney Patients

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www.Baakp.org

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an electronic version of this newsletter.

BAAKP Creates New Drop-In Patient Support Groups!

In addition to our regularly scheduled Education Meetings, we are testing a new format of small, regular support group meetings. These occur more frequently than the Educational Meetings and require no pre-registration. There have been 5 so far: in October, November, February, March & April. Any and all topics are covered and are driven by what YOU want to discuss! The next meeting dates are July 15,2012 and October 21, 2012. Drop in and hear what your fellow kidney patients have to say. As with our Educational Events, these are held at the Palo Alto Medical Foundation on the third floor from 1-3 pm on designated Sundays. We'd love to have you join us!

Other Kidney Support Groups

AAKP
American Association of Kidney Patients

Has many resources available both on their website & through their publications.

3505 E. Frontage Rd.
Suite 315
Tampa, FL 33607
(800) 749-2257

www.aakp.org

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, Conference Room G, 2500 Grant Road, Mountain View, CA 94040
www.bayareatrio.org
(408) 353-2169

San Francisco Polycystic Kidney Foundation

For general PKD information, call:
1-800-PKDCURE

For information about local groups, go to:

www.pkdcure.org/sanfranciscochapter

For chapter specific questions, please send email to:
sanfranciscochapter@pkdcure.org

The National Kidney Foundation of No. California & No. Nevada

Has many resources available and sponsors many events.
For more info:
www.kidneynca.org
(415) 543-3303

National Kidney Foundation
www.kidney.org

Bay Area Association of
Kidney Patients

Educating and Supporting Bay Area Kidney Patients

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

Winner of the Best Kidney Patients' Support Group Award from the AAKP

SAVE THE DATES!

All meeting are held on the 3rd floor of PAMF.
795 El Camino Real, Palo Alto, CA 94301.

Educational Events

May 20, 2012
Polycystic Kidney Disease

September 23, 2012
Peritoneal Dialysis

Support Group Meetings

July 15, 2012
October 21,2012

Board 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)
info@baakp.org (650) 323-2225

Coming soon: Living with PKD and Other Genetic Kidney Diseases

We are fortunate to have 2 very special speakers for our **May 20, 2012** live presentation on "Living with Polycystic Kidney Disease (PKD) and Other Genetic Kidney Diseases." **Robert Weiss, MD** from University of California at Davis will discuss Polycystic Kidney Disease and the latest on diagnoses and treatment.. **Gary Frohlich, MS, CGC (Certified Genetic Counselor)** will talk about other inherited kidney diseases There will be a patient panel, ample time for audience questions, and a social hour. Kidney-friendly refreshments will be served. Join us for this FREE presentation! More information and a map are available on our Events page at our website www.baakp.org. This event is generously supported by **Genzyme**., Inc.

Time: 1 to 4 PM, Sunday May 20, 2012, with complimentary refreshments and a social hour to follow. All are welcome.

Location: 3rd floor conference room of the Palo Alto Medical Foundation, 795 El Camino Real, Palo Alto, CA 94301 .

Your RSVP is kindly requested. To reserve your seat, email us at **info@baakp.org** 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.