

American Association of Kidney Patients-Bay Area Chapter*

*unchartered

Volume 1, Issue 1

November 30, 2007
Fall 2007 Issue

A Contest to Name Our Newsletter!

Welcome to the first edition of the newsletter for the Bay Area Chapter of the American Association of Kidney Patients!

We need a name! Notice the blank space in the oval part of the masthead. Please send your suggestions to

bay.area.kidney@gmail.com
Or by mail to
P.O. Box 2332
Menlo Park, CA 94026-2332

The winner will receive a \$25 one-year membership to the American Association of Kidney Patients. Entries are due January 30, 2008.

Chapter Officers

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April Ellis, Bea Goodman
Toby Gottheiner, M.D.,
Anne Griffin, John Hatfield
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Dr. Gottheiner Speaks to Kidney Group

By Jeanne Heise

Toby Gottheiner, M.D. spoke at the first meeting of the Bay Area Chapter of the American Association of Kidney Patients on October 20, 2007 to the assembled audience of chronic kidney patients, caregivers, and health care professionals on the topic of "Chronic Kidney Disease: Staying One Step Ahead." Dr. Gottheiner is a noted nephrologist, previously recognized by the San Jose Magazine as one of the top 100 doctors in the Bay Area.

Dr. Gottheiner's presentation included material on identifying people at risk, the stages of chronic kidney disease, complications of the disease, preparation for dialysis and transplant, and understanding the nature of Stage 5 kidney disease.

With the incidence of kidney disease at 17 % of the population and rising, it is impera-



Toby Gottheiner, M.D. with Pat Barr, kidney donor

tive to have early identification of people at risk of developing the disease. The earlier the patient becomes aware of their disease, the easier it is to estimate the progression of the disease, to anticipate the complications, to discuss treatment options and plan accordingly.

Dr. Gottheiner urged patients to become better informed about the state of their health, to know their numbers, to understand the diagnostic tests, to ask questions and seek second opinions, and work to

modify risk factors such as diet, blood pressure, obesity, underlying disease, and exercise. He said it is extremely important for the patient to be aware of the progression of the disease, and treatment options, so they can work as a team with their primary care physicians and nephrologists.

When the time comes to consider dialysis and transplant, the doctor and patient can again work together to make sure the patient stays well informed about dialysis options, receives appropriate referrals to transplant programs, and is prepared to deal with the prospect of Stage 5 kidney failure.

It is only through working as a team, as a partnership between medical professionals and patients, that chronic kidney disease sufferers can gather the knowledge they need to stay one step ahead of the disease and continue to lead productive and active lives.



Dr. Toby Gottheiner introduces his talk

First Fund Raiser Garage Sale Held in September 2007

The first Garage and Bake Sale to benefit the treasury of the local Bay Area AAKP Chapter (unchartered) was on September 8, 2007, at the home of Walt and Linda Umbach.

Misako Gambe, Bea & Sam Goodman, Tomomi Barron and Betsy Buchter all contributed items, which combined with the items in the Umbach's garage resulted in quite a pile of goods

to sell! Even the Umbach granddaughters cheerily staffed the Bake Sale Table. Thanks also to Misako for help with pricing!

The event netted \$419 and another one is planned for the Spring of 2008— So remember to **Save Your Stuff!**

(We're looking for volunteers to help with the Spring Garage and Bake Sale!)



Patrick & Tomomi Barron's twin pugs raised money at the Garage Sale by selling \$1.00 kisses!

Other Local Kidney Support Groups & Meetings

The National Kidney Foundation

(NKF) is sponsoring a **Chronic Kidney Disease Forum:**

Self-Management, Peer Education and Advocacy

On Sunday, December 2, 2007

1:30-4:30 pm,

reception 4:00 to 6:00 pm

at the Hyatt Regency Hotel, 5 Embarcadero Center, San Francisco, CA 94111

Register at www.kidneyca.org or at 415-543-3303 ext #110

T.R.I.O

Transplant Recipients International Organization-
San Francisco Bay Area Chapter

Meets on the 2nd Thursday of each month at 7:30 pm at El Camino Hospital Cafeteria Meeting Room, 2500 Grant Road, Mountain View, CA 94040

For more info:

www.bayareatrio.org

408-353-2169

Chapter Works on Application

Your Steering Committee (Officers and Board of Directors) just received notice that they are encouraged to submit their application of The Bay Area Chapter of the American Association of Kidney Patients for approval by the Board of Directors of the national organization in Tampa, Florida.

This is the news we have been awaiting; the Steering Committee is now madly working to complete the application by the December 17, 2007, deadline. Approval could come at the late January 2008 meeting of the National Board of Directors! Once we are an official chapter we will qualify for 501 c(3) tax exempt status and can solicit sponsorships!

Today's Joke



...and this dish is totally potassium-free!

Cartoon by Peter Quaife, a Canadian dialysis patient From his book The Lighter Side of Dialysis, Volume 1 Copyright 2005 by Jazz Communications, Ltd.

Introducing the American Association of Kidney Patients

At the first Informational Meeting of the American Association of Kidney Patients-The Bay Area Chapter (pre-charter), Steering Committee Chairperson Linda Umbach introduced the AAKP.

The AAKP began as a group of 6 New York dialysis patients in 1969, as they sat through primitive dialysis that often lasted 12-18 hours.

Initially, they fought for the enactment of the Federal Medicare End Stage Renal Disease Program. One of their members even testified before the House

Ways & Means Committee while undergoing dialysis. They were successful in 1972, when Congress enacted Medicare funding for dialysis and transplantation.

Today, AAKP has 12,000 members, and reaches over 1 million persons per year with various programs.

The goals of AAKP are:

EDUCATION

SUPPORT

ADVOCACY

AAKP also sponsors a yearly 4

day convention over Labor Day Weekend. For 2008, the convention will be in Washington, D.C.

There are 11 local Chapters; our group is attempting to become the 12th!

Membership in the National AAKP entitles you to membership in the local chapter and it is only \$25.00 per year. Come join us in creating a San Francisco Bay Area Chapter!

Visit www.aakp.org



Kidney Patients Taking Control

By Constantia Petrou, Ph.D.

The 76 year old John Hatfield, the 22 year old Ryan Barr and the 56 year old Joel Riff, though at different stages in life, had a common message to share when it comes to managing kidney disease: Stay positive, active and in control with the help of your family, doctor and friends.

John focused on compliance and shared his "compliance kit": a blood pressure monitor, a memory organizer book and a deck of cards that reminds him how much protein he can eat per day. This represented his journey of first managing hypertension and then kidney disease. For him, half of winning the battle is admitting you have the disease and the other half is having people you can rely on: his late wife and now his poker group that holds "organ recitals" to talk about "how our kidneys, heart, what have you- are doing".

Ryan received a kidney transplant from his mother a year ago. His life was abruptly changed literally over night when he woke up swollen with an extra 30 pounds and a diagnosis of Focal Segmental Glomerulosclerosis. "It was a roller coaster ride... we went from knowing nothing to a crash course on kidney disease and learned to ask ahead of time: 'What can I do?'. Pat, his mother, has been there all the way giving him the ultimate gift. With tears in her eyes she shared that "it didn't take a second to make the decision [to donate]. I would do it for anyone I care about."

Joel's way of staying active is his full time job and his travel. He sees his hemodialysis treatments 3 times a week for 3 hours at a time as something to "fit into my life". In fact, it is his life style that has been the driver behind his treatment decisions for kidney disease. Joel started with home peritoneal dialysis because

of the flexibility it afforded him to travel. After a serious infection he had to switch to hemodialysis at a clinic but this hasn't stopped him from traveling to major cities. He just has to plan ahead to have his dialysis done at his destinations. Joel feels that because he found a doctor he can trust and discuss options with, he can make informed decisions: decisions he feels good about and that fit his life.

All three panelists were inspirational in different ways. John motivated an attendee to get her own blood pressure monitor. Others were impressed by Ryan's recovery and zest for his new life, while some were motivated by Joel to find out more about additional treatment options.



Panelists Joel Riff and John Hatfield

**American Association of
Kidney Patients-Bay Area
Chapter***

*pre-charter

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**Organized
by Kidney Patients
for Kidney Patients**

*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 13, 2008**
Sunday, 1:00 pm
Steve Katznelson, M.D.
Transplant Nephrologist
California Pacific Medical Center
in San Francisco
"Paired Transplantation"
- **Sunday April 13, 2008**
- **Sunday June 22, 2008**

**Steering Committee
Meetings**

- **First Tuesday of
every month at 5:30 pm**

*If you would like to join us in the
formation of this chapter of the
AAKP, we would love to have your
help. (call for location)*

More info:

**bay.area.kidney@gmail.com
650-326-2107**

Katznelson to speak at January Meeting

We are indeed privileged to welcome as our featured speaker for our January 13, 2008, meeting, to be held at Sequoia Hospital, Steve Katznelson, M.D., Medical Director of the California Pacific Medical Center Kidney and Pancreas Transplant Program and Vice Chairman of the CPMC's Department of Transplant. The developer of the new "paired exchange" program at the medical center, Dr. Katznelson will describe Developments in Living Donation-Identical Twins to Paired Donation, an short historical retrospective plus an in-depth review of the latest transplant techniques. He will also spend time fielding inquiries from the audience; so bring your questions and be prepared to have them answered by an expert!

California Pacific Medical Center in San Francisco transplants about 200 kidney patients a year plus 20-30 combined kidney/pancreas transplants for diabetic patients. The CPMC Kidney Transplant Team's success rates outperform the national averages as reported by the most recent data from the Scientific Registry of Transplant Recipients (www.ustransplant.org). The

Team consists of 5 transplant nephrologists, 4 Surgeons, 15 Nurses, 4 Social Workers, and 2 Financial Coordinators.

We are also fortunate to have as our guest panel various members of the CPMC Transplant Staff, describing when you as a patient would encounter them and the specific role each plays. The panel will be moderated by a transplant patient. Panel members will include several nurse coordinators and social workers who will discuss and answer questions about kidney transplant from the initial evaluation through the post-transplant phase (including medications).

This event is not to be missed; reserve your seat now! Email us at bay.area.kidney@gmail.com or call us at **650- 326-2107** . You can also fax us at **650-327-0178** or write to **P.O. Box 2332, Menlo Park, CA 94025-2332**

