

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

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Living with Polycystic Kidney Disease

by Patrick Barron

BAAKP's meeting on May 20th, 2012 focused on genetic kidney diseases, with Polycystic Kidney Disease (PKD) being in front and center. The group was honored to have Dr. Robert H. Weiss, Nephrologist, University of California, Davis, talk about PKD that affects 500,000 people in the US and 10,000,000 worldwide. Dr. Weiss delivered a comprehensive overview of the disease from its genetic causes, through the symptoms, risks, complications and treatments. In addition he presented important findings from new studies on the disease.

PKD is characterized by the continuous growth of numerous cysts in both kidneys. Over a period spanning decades the cysts enlarge damaging the organ's structures resulting in kidney failure in over half of patients. While there is still no cure for the disease, in the last ten to fifteen years since the genes were identified, there have been rapid advances in understanding the disease raising hopes for a cure.

Dr. Weiss focused his talk on Autosomal Dominant Polycystic Kidney Disease (ADPKD) that is by far the most common form of the disease. ADPKD is associated with mutations in the

PKD1 and PKD2 genes, while the recessive form of the disease is associated with the PKHD gene. Each child born to a parent with ADPKD has a 50% chance of inheriting the disease. More recently however, it appears that as many as 20-40% of PKD patients develop the disease from new or "de

novo" mutations, meaning neither parent carries the disease. PKD1 mutations, found in 85% of patients, result in a more rapid disease progression with half of patients facing end stage renal disease (ESRD) between the ages of 40 and 65. By contrast, of the 15% of patients who have a PKD2 mutation, only 7% experience ESRD by the age of 60.

Early PKD symptoms that are not unique to the disease include pain in the back and lower sides, headaches, urinary tract infections, cysts in the liver and pancreas, and blood in the urine. Knowing a parent has the disease of course increases the likelihood of a patient having PKD. However, it still requires an ultrasound, MRI or genetic testing to diagnose the disease.

With a few important exceptions the treatment of PKD follows that of other kidney diseases and at all stages of the disease, PKD patients do especially



Dr. Weiss from UC Davis delivering his talk on Polycystic Kidney Disease

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well. However Dr. Weiss took time to make clear the additional cardiovascular risks associated with PKD are major causes of complications and death. These include hypertension, left ventricular hypertrophy (LVH) which is the thickening of the heart wall that can cause heart failure, heart valve abnormalities and brain aneurisms, that are rare but can be life threatening.

Current consensus recommendations by PKD experts include the early and aggressive treatment of hypertension with ACE inhibitors or ARBs is especially important. ACE inhibitors and ARBs are a class of blood pressure medicines that lower the level of angiotensin that constricts the blood vessels. However, women who are pregnant or of childbearing age should use other blood pressure medications (e.g. Aldomet), or very reliable birth control methods. Blood pressure should be maintained below 120/80. Even in cases where blood pressure is normal, but there is protein in the urine or LVH is present, ACEI and ARB medications are recommended. Smoking cessation, weight management, limiting sodium intake and exercise also play an important role in controlling hypertension. Closely monitoring and managing blood pressure helps slow the progression of cyst growth, reverses LVH, and lowers the risks of strokes and cerebral aneurisms.

The PKD1 and PKD2 genes encode for proteins that are expressed in the tubular structures of the kidney as well as in the vascular system beyond the kidneys. Mutations in these genes appear to be tied to the heart valve abnormalities found in some PKD patients affecting the mitral, aortic and tricuspid valves. These abnormalities are typically detected through a heart murmur on a stethoscope exam. Further investigation is done through an echocardiogram. While in most cases the problem is mild and can be ignored, it should be frequently monitored. In rare cases surgery may be necessary.

While quite rare, PKD can also cause brain or intracranial aneurisms in patients. The occurrence of aneurisms runs in certain PKD families. All patients need to be aware of this risk and seek im-

mediate medical attention in event of the onset of a sudden and severe headache. When visiting an emergency room or calling 911, patients should make sure the staff is informed about the PKD diagnosis and the related risk of cerebral aneurisms. Screening through an angiogram (if kidney function is okay) is recommended in all PKD patients in high-risk occupations such as airplane pilots or bus drivers and especially when there is a family history. Treatment is through surgery.

For the over fifty percent of patients where the disease progresses to kidney failure, dialysis (HD and PD) or a transplant are the treatment options, with a kidney transplant being the preferred choice. The good news with a transplant is the disease does not affect the transplanted kidney.

Dr. Weiss presented two new treatment recommendations resulting from recent research. The first is a truly novel finding by which PKD patients can slow the disease progression simply by drinking lots of water from an early stage of the disease. It turns out that drinking lots of water expands a patient's blood volume that in turn

has the effect of decreasing the level of a hormone called vasopressin that is known to worsen the progression of PKD. However, this is not recommended for patients who have heart problems. The second finding relates to

the effect of pregnancy on disease progression. Indications are that repeated pregnancies may accelerate the progression of PKD.

Dr. Weiss expressed a new excitement and optimism in the field on finding a cure for PKD in the next ten to twenty years thanks to new level of research interest and funding available to study the disease. Additionally as the mechanism for the disease is being uncovered, areas of similarity to other diseases expands both the knowledge base and toolset available to find a cure.



Attendees hear a Patient Panel member describe life with PKD

Thank You to Our Speakers and Sponsors!

The BAAKP is a non-profit organization supported by grants, donations and volunteers. We would like to thank and recognize the following for their contributions to the presentation on **Polycystic Kidney Disease** that was held on May 20, 2012.

- The **Palo Alto Medical Foundation**: for providing the use of their facility not only for this event but also for all of our support group meetings.
- Our Sponsor: **Ginger Gradeff** and her employer **Genzyme Corporation** for providing a grant to support this event.
- Our Speakers for sharing their expertise in this field:
 - Dr. Robert Weiss**, UC Davis Division of Nephrology
 - Mr. Gary Frohlich**, Certified Genetics Counselor, Genzyme, Corporation.
- Our Patient Panel who described what it is like living with PKD:
 - Valen Cover Keefer**
 - Katherine Michiels**
 - Patrick Barron**
- Our local merchants for providing gifts and prizes:
 - Trader Joes** in Menlo Park (720 Menlo Avenue)
 - Draeger's** in Menlo Park (1010 University Avenue)
 - Costco** in Redwood City (2300 Middlefield Road)
 - Starbucks** in Menlo Park (Santa Cruz Avenue)

It is willingness of everyone listed above participating in our events that makes it possible for BAAKP to continue with these first rate presentations and our mission to **Educate and Support Bay Area Kidney Patients**.

Thank you so much!

Other Kidney Support Groups

<p style="text-align: center;">AAKP American Association of Kidney Patients</p> <p>Has many resources available both on their website & through their publications.</p> <p>3505 E. Frontage Rd. Suite 315 Tampa, FL 33607 (800) 749-2257</p> <p style="text-align: center;">www.aakp.org</p>	<p style="text-align: center;">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, Conference Room G, 2500 Grant Road, Mountain View, CA 94040</p> <p style="text-align: center;">www.bayareatrio.org (408) 353-2169</p>	<p style="text-align: center;">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 style="text-align: center;">The National Kidney Foundation of No. California & No. Nevada</p> <p>Has many resources available and sponsors many events. For more info: www.kidneyncanv.org (415) 543-3303</p> <p style="text-align: center;">National Kidney Foundation www.kidney.org</p>
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Traveling with an Overnight “cyclor” for Peritoneal Dialysis

International travel has been an important part of John Hatfield’s life, even after he began dialysis in 2008. But now he has a new travel companion; a carry-on bag with his “cyclor”, an overnight Peritoneal Dialysis machine. You see, John opted for overnight Peritoneal Dialysis, in part, because of the travel flexibility it offered. And travel he has! His two most recent trips have been a European tour ending with a Baltic Cruise and a trip to Australia.

He flew to Europe with his sister and stayed in Paris with their cousin for a few nights, before leaving for Ouessant (fr.) or Ushant, a small island in the (English) Channel, spending several nights at their cousin’s vacation home. John and his sister returned to Paris and then on to Copenhagen, flying each step of the way. There, they boarded a Holland America ship cruised the Baltic Sea. Ports were visited in Germany, Estonia, Russia, Finland, Sweden and Norway.

His trip to Australia with his daughter took two weeks. They flew into Sydney and then on to Kangaroo Island which had unique wildlife species. They also visited Adelaide, Cairn and Brisbane, where they stayed with friends.



l to r - cousin Betty, sister Sally and John on the island Ouessant

John credits his wonderful travel agent and the folks on the International Travel Desk at Baxter Inc., for arranging his peritoneal dialysis along the way. But he cautions that it is important to plan ahead,

“way ahead”. He made his arrangements with Baxter two months in advance. Baxter supplied the dialysate liquid for John to use with his cyclor. At each step of the way for both trips, the dialysis supplies were waiting for him when he arrived. John carried the equipment with him, the 25# cyclor had to be hand carried; it is too delicate to be included in the checked baggage. The 18# transformer was in his baggage, along with tubing, outlet adaptor plug, and sterile cassettes.

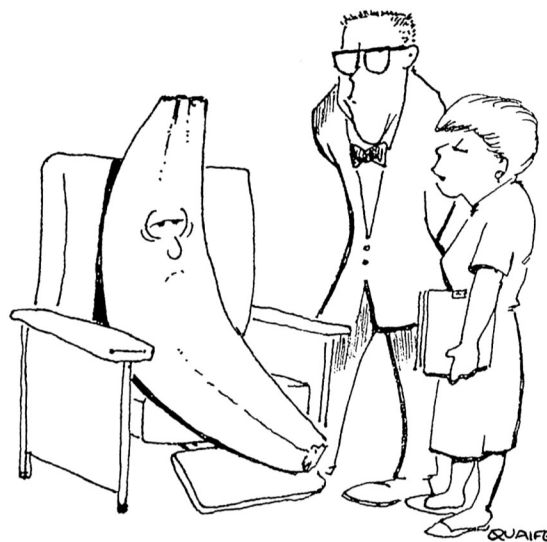
He had also checked with the hotels, to verify that they can accept and store the volumes of dialysate fluid that are necessary. He estimates he used 12,000 ml of fluid per night.

John recommends that you carry a “medical letter of necessity” from your doctor that explains the equipment to airline security. Research and take the names of hospitals and clinics near your destinations and be sure to take your medical records. He also says to never check your medicines; keep them with you in your carry-on bag.

John cautions that you “have to be flexible”. Three days prior to his arrival, when he checked with his cousin’s neighbor on the Ouessant he learned that his supplies had not been delivered. But after several quick phone calls, the needed supplies arrived before John did!

Kidney professionals state that the ability to travel is very important to the kidney dialysis patient and positively affects the patient’s sense of well-being. Being able to dialyze on the road enables the patient to attend business meetings and important family events. And most importantly, “On the Road” dialysis is essential for that travel you planned for your retirement.

For more information: <http://homedialysis.org/article/life-at-home/leaving-on-a-jet-plane-fly-ing-with-a-pd-cyclor-or-nxstage-system-one>



We’re a little concerned about your potassium levels.

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

The 2012 Membership Survey - The Results Are In!

Bay Area Association of Kidney Patients Board Members **Ben Lee** and **Grant Bennett** organized the most recent survey of our BAAKP members and presented the results to the BAAKP Board of Directors on May 9, 2012. As with our original survey in 2009, this was conducted primarily using internet tools, with only about 80 copies mailed by the USPS to those without internet service or email. Thanks to all of you who responded, we have some great results to summarize!

- When asked how you heard about BAAKP, 24% replied from doctors' office or contact (flyers) and 24% from a BAAKP member.
- Was presentation beneficial? 76% said yes. 55% of the respondents had attended at least 2 of our meetings.
(20% of responders never attended a meeting-they said they get all their information from our newsletters!)
- 33% replied they were in Stages 1-4 and 31% had already received a kidney transplant.
- 77% were satisfied or very satisfied with the presentations; (22% of respondents had never attended a presentation.)
- 57% enjoyed the social hour and 65% enjoyed the refreshments (Interesting...)
- Surprisingly, 68% of the respondents have never viewed our website (www.baakp.org)

We are very proud to say that 66% of the respondents said their condition was improved; 61% have changed their lifestyle; 75% said they feel better after our presentations and 75% feel less isolated with their disease.

The BAAKP Board Members feel rewarded to see that our efforts have improved the lives of so many kidney patients and appreciate the many great comments. Thank you for helping with our 2012 survey; additionally, these results will support our requests for grants and sponsorships!



Bay Area Association of
Kidney Patients

Stay updated!

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CTRL/click the links when reading an electronic version

This newsletter is not intended to take the place of personal medical advice, which should be obtained directly from a physician. Please consult your physician about any changes or additions you make to your kidney care.



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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 help is greatly
appreciated!

Winner of the 2010 Best Kidney Patient Support Group Award from the AAKP

SAVE THESE DATES !

Educational Events

- **September 23, 2012**
Diabetes and Kidney Disease
- **January 27, 2013**
Peritoneal Dialysis

Support Group Meetings

- **October 21, 2012**
- **November 18, 2012**
- **February 24, 2013**

Educational Events (1-4 pm) and Support Group Meetings (1-3 pm) are held on the third floor of PAMF, 795 El Camino Real, Palo Alto, CA 94301

Board of Directors' Meetings **2nd Wednesday of the 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

Staying Ahead of Diabetic Kidney Disease with Dr. Vivek Bhalla Nephrologist, Stanford Hospital and Clinics



On September 23, 2012, please join us for the Bay Area Association of Kidney Patients' **5th Birthday** Celebration to meet past and present BAAKP speakers, sponsors & volunteers. Learn about the organization's achievements, and listen to inspiring stories of patients who do not let illness rule their lives. Enjoy **Birthday Cake** too!

Returning by popular demand will be the guest speaker, **Vivek Bhalla, M.D.** Assistant Professor of Medicine at Stanford University, and Fellow of the American Society of Nephrologists. He will share the latest in Diabetes and Kidney disease research and treatment and answer your questions. Also present will be the ever-popular **Patient Panel** with their personal stories.

This **FREE** event will be at the Palo Alto Medical Foundation, 795 El Camino Real, 3rd floor conference room, Palo Alto, CA 94301 on Sunday, September 23, 2012 from 1 to 4 pm. There will be ample time for social interaction and patient support. Kidney-friendly refreshments (and Birthday Cake) will be served! To reserve your seat, please email your **reservation to info@baakp.org or call 650-323-2225.**

Underwritten by [Fora Care, Inc.](http://ForaCare.com) Medical Devices, this event is presented with the cooperation of tudiabetes.org.

